STABLE LOVE, STABLE LIFE?

The role of support and acceptance in relationship satisfaction of couples living with Menière's disease.

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Preface

This study of couples living with Menière's disease was conducted for the master thesis of the Master Social Psychology of the University of Groningen. The committee Menière of the Dutch patient organization NVVS approached the Science Shop of the UMCG with the request to examine the influence of Menière's disease on the lives of patients and their partners within their relationship. This study was of particular importance since the role of support and acceptance in relationship satisfaction rarely has been investigated among couple's living with Menière's disease.

In particular I want to thank my supervisors Dr. J. Tuinstra of the Science Shop UMCG and dr. T.V. Pollet of the University of Groningen, for their inspiration and enjoyable supervision. Additionally I want to thank dr. J. Bouma and dr. R. Bakker for their guidance in the beginning of the research project and dr. M. Schokker for sharing her experience. Specifically I am grateful for the commitment and involvement of Mrs. S. Rutgers, public health physician and chairperson of the Committee Ménière of the NVVS and for the comments of P. Demacker, PhD, biochemical expert and volunteer for the NVVS. I want to thank C. Verkuijl and L. Lenting for their helpful comments on the English language. Without the couples who filled out the questionnaire this project would not have been possible and I want to thank them heartily for their participation. Last but not least I want to thank my colleagues of the Science Shop UMCG, my friends and family, and in particular my partner for their active engagement during this study.

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Marise Kaper

Summary

Background: Menière's disease is a chronic illness which consists of three main symptoms: vertigo attacks, tinnitus and hearing loss. Menière's disease affects patients and their partners since the disease can be stressful and disabling. Patients and partners are interdependent within their relationship and they support each other in dealing with Menière's disease. This support is possible through active engagement (actively talking about problems and sharing of feelings) or protective buffering (avoiding talking about problems and feelings). The main question is how Menière's disease influences the lives of patients and their partners within their relationship. We examined the role of support (active engagement and protective buffering), quality of life and acceptance in relationship satisfaction of patients and partners.

Method: In this cross-sectional study, 426 patients and their partners who were contacted by the Dutch Association of Aurally handicapped people (NVVS in Dutch) filled out the questionnaire. A total of 142 couples were included in this study (142 patients and 142 partners). Patients and partners filled out a questionnaire which measured relationship satisfaction, support, acceptance and quality of life.

Results: We found that patients and partners were more satisfied with their relationship when they perceived more active engagement from each other, in particular female patients. Protective buffering had a slightly negative impact on relationship satisfaction. Active engagement was particularly important for male patients and female partners with higher levels of anxiety and depression. When they perceived more active engagement they reported higher relationship satisfaction. Acceptance of Menière's disease was able to take away the negative influence of a poorer quality of life and protective buffering on relationship satisfaction of patients. For male partners acceptance was important too, as it partially took away the negative impact of anxiety, depression, lower vitality and protective buffering on their relationship satisfaction. Acceptance had no influence on female partners. Active engagement was the strongest predictor of relationship satisfaction and the second strongest was acceptance.

Conclusion: Couples are interdependent in their relationship and active engagement was important for everyone in dealing with Menière's disease. Females view themselves as more interdependent and connected in relationships with others compared to men and active engagement is particular important for them. It is important to examine specific needs of individuals in a relationship, since acceptance was important for the relationship satisfaction of patients and male partners, while acceptance had no influence on relationship satisfaction of female partners. We can recommend relationship counseling for patients and partners who face problems in dealing with Menière's disease, since it can improve their relationship satisfaction and other circumstances in which they live.

Samenvatting

Achtergrond: De ziekte van Ménière is een chronische ziekte die bestaat uit drie symptomen: aanvallen van duizeligheid, tinnitus en gehoorverlies. De ziekte van Ménière kan stressvol en belemmerend zijn en raakt patiënten en hun partners. Patiënten en partners zijn onderling afhankelijk in hun relatie en ze ondersteunen elkaar in het omgaan met de ziekte van Ménière. Het bieden van ondersteuning kan door actieve betrokkenheid (actief praten met elkaar over problemen en het delen van gevoelens) of door beschermend bufferen (het vermijden van het praten over problemen en gevoelens). De hoofdvraag is hoe de ziekte van Ménière de levens van patiënten en hun partners beïnvloedt in hun relatie. We onderzochten hierbij de invloed van ondersteuning (actieve betrokkenheid en beschermend bufferen), kwaliteit van leven en acceptatie op de relatietevredenheid van patiënten en hun partners.

Methode: In deze cross-sectionele studie ontvingen we 426 ingevulde vragenlijsten van patiënten en hun partners nadat zij waren benaderd door de Nederlandse Vereniging voor Slechthorenden (NVVS). In totaal werden 142 paren (142 patiënten en 142 partners) opgenomen in deze studie. Patiënten en partners vulden een vragenlijst in over relatietevredenheid, ondersteuning, acceptatie en kwaliteit van leven.

Resultaten: We vonden dat patiënten en partners tevredener waren met hun relatie wanneer ze meer actieve betrokkenheid waarnamen van elkaar, dit gold voor vrouwelijke patiënten in het bijzonder. Beschermend bufferen had een geringe negatieve invloed op relatietevredenheid. Actieve betrokkenheid was vooral belangrijk bij mannelijke patiënten en vrouwelijke partners met een hogere mate van angst en depressie. Wanneer zij in dit geval meer actieve betrokkenheid waarnamen, dan waren ze ook tevredener met hun relatie. Acceptatie van de ziekte van Ménière was in staat om de negatieve invloed van een slechtere kwaliteit van leven en beschermend bufferen op relatietevredenheid van patiënten weg te nemen. Voor mannelijke partners was acceptatie eveneens belangrijk, want acceptatie kon gedeeltelijk de negatieve invloed van angst, depressie, slechtere vitaliteit en beschermend bufferen op de tevredenheid met hun relatie wegnemen. Acceptatie had geen invloed op relatietevredenheid van vrouwelijke partners. Actieve betrokkenheid was de sterkste voorspeller van relatietevredenheid en acceptatie was de op een na sterkste factor.

Conclusie: Koppels zijn wederzijds afhankelijk in hun relatie en actieve betrokkenheid is voor alle groepen belangrijk. Vrouwen zien zichzelf meer dan mannen als wederzijds afhankelijk in relatie tot anderen. Voor hen is actieve betrokkenheid extra belangrijk. Het is belangrijk om specifieke behoeften van individuen te onderzoeken, want acceptatie was belangrijk voor patiënten en mannelijke partners, maar niet voor vrouwelijke partners. Voor koppels die problemen ervaren met de ziekte van Ménière is relatietherapie aan te bevelen want dit kan relatietevredenheid en leefomstandigheden verbeteren.

1. Introduction

1.1 Couples living with Menière's disease

In an intimate relationship, two individuals share a social world with common interactions and experiences. They can be viewed as interdependent in their relationship (Bodenmann, 2005; Rusbult & Buunk, 1993). Within this relationship there are differences between males and females in the degree of interdependence (Cross & Madson, 1997).

Yet, what happens in this intimate relationship if one of the individuals has Menière's disease? This is the subject of the current study. In Menière's disease three symptoms are involved, which are vertigo, hearing loss and tinnitus. At this moment there is no medical solution for Menière's disease and patients as well as their partners have to learn to live with this disease. Under these circumstances Menière's disease can be perceived as a long-term stressor, which influences the quality of life of both partners and their relationship (Berg & Upchurch, 2007; Kuyper, 1993). The prevalence of Menière's disease ranges from 4 to 157 per 100.000 people but this number differs per country (Schessel, Minor & Nedzelski, 2005). Based on these figures it has been estimated that there are over 10.000 patients with Menière's disease in the Netherlands (Van Cruijsen, Jaspers, Van De Wiel, Wit & Albers, 2006). Research on both partners adapting to Menière's disease is rarely done. Studies focused mainly on the individual coping strategies of patients. Individual coping implies the attempts to manage the stressors of their disease to return to normal functioning (Ogden, 2007). According to Folkman and Lazarus (1984) this coping can be problem-focused (manage actions to deal with the stressor) or emotion focused (managing the emotions evoked by the stressor). Berg and Upchurch (2007) and others have extended the ways of individual coping to a model of interdependent individuals supporting each other in adapting to a chronic illness. This support model offers more insight how Menière's disease influences the life of patients and partners within their relationship.

1.2 The support model

The support model of this study is presented in figure 1.1. The main components are the same as in the study of Berg and Upchurch (2007). Appraisal of the influence of Menière's disease (MD) is the first component. This is including quality of life, which is viewed as an evaluation by patients and partners of their physical and psychological health (Hagedoorn et al., 2000; Van Cruijsen et al., 2006). The second component is the support both partners perceive from each other in order to cope with the disease. Relationship satisfaction is an evaluation of the quality of a relationship. The third component is relationship satisfaction,

which is the outcome variable in this study. Acceptance of the disease was added to make the support model more suitable to MD. Higher acceptance was an important predictor of a better quality of life in a study with Menière patients (De Vries, 2011). Menière's disease can be difficult to control and acceptance changes the perception in diminishing the negative consequences of the disease (Evers, Kraaimaat, Van Lankveld, Jacobs & Bijlsma, 1998). Adapting to MD can be easier through acceptance (Scarinci, Worral & Hickson, 2008). The influence of the components on relationship satisfaction was investigated for patients and partners. This process is indicated by the thin straight arrows.

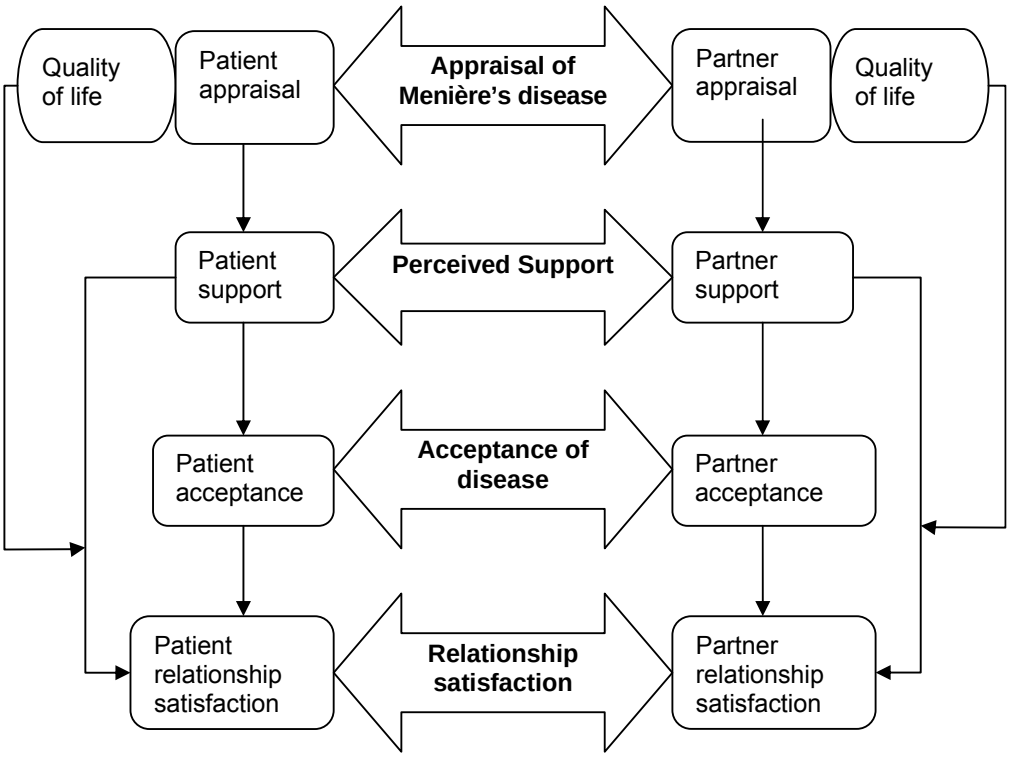


Figure 1.1. Model of support, acceptance and relationship satisfaction in Meniere's disease.

Patients and partners start with an evaluation of Menière's disease and their quality of life, as shown in Figure 1.1. In the next step couples support each other in adapting to the disease. Two ways of support are active engagement (AE) and protective buffering (PB), (Coyne & Smith, 1991, 1994; Buunk, Berkhuysen, Sanderman & Nieuwland, 1996). AE refers to the phenomenon that couples actively share their thoughts and feelings and talk about problems. PB refers to the phenomenon that couples avoid talking about problems and avoid sharing thoughts and feelings. The way partners support each other influences their relationship satisfaction (Hagedoorn et al., 2000; Schokker et al., 2010; Buunk et al., 1996). Supporting each other can be easier when both partners accept Menière's disease (Scarinci et al., 2008).

2. Literature review

2.1 Menière's disease

Menière's disease (MD) is an inner ear disorder, which is characterized by three main symptoms: vertigo, tinnitus and hearing loss (Van Cruijsen, 2006; Mateijsen, 2001). MD usually starts with rotatory vertigo in periodic attacks, which gives patients the feeling that their surroundings are constantly moving around them. Mostly, vertigo attacks are unpredictable and they last from several hours to a whole day or even a couple of days (Crins & Kunst, 2008). During vertigo attacks patients can suffer from nausea and vomiting. They are often not able to carry out their normal daily activities. The vertigo attacks lead to hearing loss. In the initial stages of the disease, beginning hearing loss fluctuates (Van Cruijsen, 2006), but hearing loss and the loss of speech discrimination eventually become permanent. Tinnitus, which can be a consequence of hearing loss, means that someone hears sounds with no external source responsible for the sound. In a later stadium of MD tinnitus and hearing loss are more prominent, while the frequency of vertigo attacks diminishes (Thorpe & James, 2005). Prosper Menière (1799-1862) was the first physician to describe MD in the Gazette Médicale de Paris (Menière, 1861). He postulated that the symptoms of MD had their origin in the inner ear, formed by the labyrinth and the vestibular organ, see Figure 2.1.

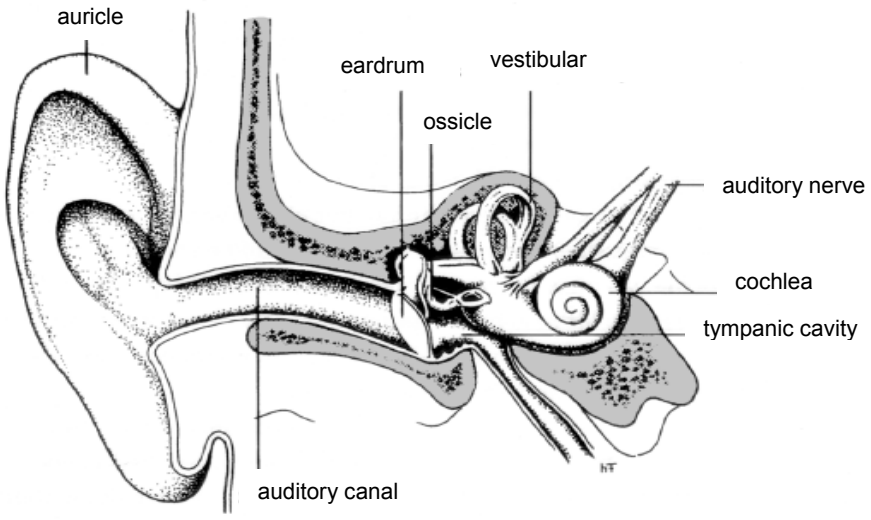


Figure 2.1. Menière's disease in the vestibular organ and cochlea (Mateijsen, 2001)

The most recent definition of Menière's disease is the 'Definition Menière Groningen', which was established by Mateijsen (2001) in the University Medical Center Groningen, together with a research protocol for patients. This operational definition has three components. The first component is a history of at least two spontaneous vertigo attacks

lasting longer than 20 minutes. The second is sensorineural hearing loss of at least 60 dB added up from the three worst octaves in the same ear, in the present or past. The third is tinnitus ipsi- or bilateral, in the present or past. MD begins in one ear, but up to 50% of the patients develop symptoms in the other ear as well. Most patients are affected by Menière's disease when they are between forty and sixty years old, while no differences have been found in men or women (Lacour, Van de Heyning, Novotny & Tighilet, 2007; Timothy & Hain, 2004; Van Cruijsen, 2006).

2.1.1 Origin and treatment of Menière's disease

As of yet, no definitive scientific evidence has been given regarding the causes of MD. The most accepted theory was proposed by Lawrence and Mc Cabe (1957), who argued that it is accumulation of fluid in the compartments of the vestibular organ, the so called hydrops of the endolymphatic system. The vestibular organ in the inner ear consists of three compartments, the scala media, scala vestibuli and scala tympani. These compartments are filled with two different chemical fluids: endolymph in the scala media and perilymph in the other two compartments, see Figure 2.2.

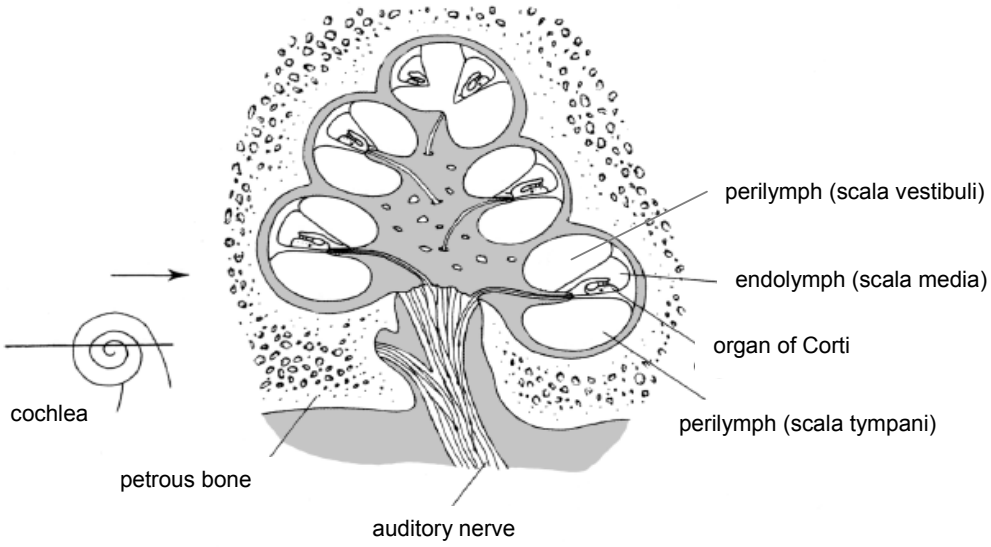


Figure 2.2. Fluid (endolymph and perilymph) in the scala media, scala vestibule and scala tympani (Mateijsen, 2001).

The endolymph in the scala media accumulates by temporary overproduction or reduced absorption (Dunnebier, Segenhout, Wit & Albers, 1997). This causes raised pressure in the scala media and leads to ruptures in the Reissner's membrane, separating the scala media from the scala vestibuli. The consequence is that endolymph leaks into the scala

vestibule, which contains perilymph. This causes a chemical reaction and generates vertigo attacks. It is likely that multiple factors, such as autoimmune reactions and viral infections interact and lead to Menière's disease (Van Cruijsen, 2006). Psychological causes of MD, like personality traits, have not been found (Yardley, Dibb & Osborne, 2003; Van Cruijsen et al., 2006). The symptoms of Menière's disease are severe and unpredictable and there is no curative treatment for MD (Van Cruijsen, 2006). Sometimes medicines, prism glasses and surgical treatment alleviate vertigo. Hearing aids can alleviate loss of hearing and tinnitus. MD can have negative consequences for the daily life of patients. Therefore, psychological treatment can also be offered in the process of adapting to this disease (Van Cruijsen, 2006).

2.2 Quality of life

Health is not merely the absence of disease, but a state of complete physical, mental and social well-being, according to the World Health Organization (WHO). Quality of life indicates how much a disease influences health and well-being of persons in their daily lives. Physical well-being has to do with physical functioning of individuals, for example the level of fatigue. Mental well-being is about the psychological functioning, for example the experienced anxiety and depression. Social well-being has to do with the functioning in social roles and activities in life, such as in work and family (Van Cruijsen et al., 2006; Yardley et al., 2003).

Quality of life is defined by the WHO as: "The individual's perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals and concerns" (Gifford, 1971). Quality of life is a subjective evaluation, since people have different interpretations of their well-being and consequences of the disease (Leventhal & Colman, 1997). People evaluate their functioning on the social, physical and mental domains, yet they differ in the value they assign to these domains. For example two individuals cannot attend concerts due to hearing loss. However, this affects one individual more than another, whereas music is more important. For patients with Menière's disease and their partners especially the following components are influential on their quality of life: anxiety and depression, severity of symptoms (vertigo, tinnitus and hearing loss) vitality, social functioning in activities and role limitations due to physical and emotional problems (Yardley et al., 2003; Van Cruijsen et al., 2006; Kuyper, 1993; Scarinci et al., 2008). Patients and partners with a poorer quality of life indicate they experience more psychological and physical health problems (Kuyper, 1993). Especially when a poorer quality of life is experienced, receiving support can have a strong impact on relationship satisfaction (Hagedoorn et al., 2000).

2.2.1 Quality of life in relation to Menière patients

Quality of life of patients with MD has been investigated by several researchers (Yardley et al., 2003; Van Cruijsen et al., 2006). Severity of vertigo had the strongest association with a poor quality of life (Yardley et al., 2003). Vertigo attacks can lead to anxiety. Due to their fear of an attack, patients have a high risk of restricting their activities. Hearing loss and tinnitus were also related to a lower quality of life (Yardley et al., 2003). For instance, hearing loss causes isolation and difficulties in communication. As tinnitus is loud and intrusive, it can lead to sleeping difficulties, fatigue and depression.

MD leads to a decrease in quality of life, which is comparable with people who have other chronic health problems (Yardley et al., 2003; Van Cruijsen et al., 2006). But compared to these groups, Menière patients reported lower levels of vitality and more physical and emotional role limitations (Yardley et al., 2003). De Vries (2011) found that Menière patients reported more anxiety than depression and experienced poorer psychological functioning compared to the general population. A higher level of depression predicted a poorer quality of life (De Vries, 2011). Patients with severe symptoms experience more anxiety and depression and use less problem focused coping strategies (Van Cruijsen et al., 2006). When patients receive more support, they have a better quality of life (Yardley et al., 2003).

2.2.2 Quality of life in relation to partners of Menière patients

Menière's disease may similarly cause partners to rearrange and restrict certain day-to-day activities, due to the impact of MD on social life. In case of vertigo attacks, the partner may have to care for the patient. Planning activities together and combining responsibilities can be complicated. Scarinci et al. (2008) signaled that social activities are more often avoided in case of hearing loss, for example due to difficulties in communication. Partners experience frustration because they frequently have to repeat things that they have said, or have to adapt to the patient in other ways. It is possible that the partners feel responsible for communication and social contacts of the patient. One study has found that hearing devices improve quality of life for both partners (Stark & Hickson, 2004). With chronic diseases of patients in general, partners experience higher levels of fatigue, anxiety and depression than partners within healthy couples (Wright & Aquilino, 1998; Kuyper, 1993). In the long term, partners of patients are required to offer more support. If they do not adapt successfully to the situation, they face a dilemma of choosing between their own needs and the needs of the patient (Kuyper, 1993).

2.3 Relationship satisfaction

Love and attraction are two possibilities that individuals engage in an intimate relationship. Yet, what are reasons that individuals choose to maintain a long term healthy relationship? In every relationship there is interaction between individuals while they are interdependent (Rusbult & Buunk, 1993). The interaction exists of mutual communication and behaviour patterns which lead to certain benefits for both partners (Thibaut & Kelly, 1959). Both partner's are connected and need each other for support, affection and other valuable benefits (Rusbult & Buunk, 1993). Individuals pursue a relationship as they are satisfied, committed and dependent on this relationship, according to the interdependence theory (Kelley & Thibaut, 1978; Thibaut & Kelly, 1959; Rusbult & Buunk, 1993).

Relationship satisfaction is defined as how satisfied partners are with the quality and functioning of their relationship on the long term (Spanier, 1979; Lewis & Spanier, 1977) and to which extent important needs are fulfilled according to a certain comparison level (Rusbult & Buunk, 1993). Individuals rely to a certain degree on a relationship to receive benefits and this dependence is related to commitment. When an individual is committed to a relationship he or she has a long-term perspective for the relationship and wants to be connected with a partner (Rusbult & Buunk, 1993). It is not only out of satisfaction that individuals pursue a relationship. Individuals compare also what kind of alternatives they have (Rusbult & Buunk, 1993). Alternatives can withhold an individual from a relationship, which can be another partner, friends or other activities. Individuals are more dependent on their relationship when the alternatives have lower attraction (Rusbult & Buunk, 1993). Commitment to a relationship increases also by investing resources, according to the investment model of Rusbult & Buunk (1993) which extends the interdependence theory. Examples of investments are time, shared emotions, friends and activities. Several studies showed a positive association between commitment, relationship satisfaction and investments (Rusbult & Buunk, 1993). Commitment correlated negatively with the attraction of alternatives. The variance of the predictors in commitment ranged from 50 to 90% (Rusbult & Buunk, 1993). Commitment fosters positive behaviour for maintaining a relationship (Rusbult & Buunk, 1993). Individuals for example have more positive thoughts about their own relationship and think more negatively about other relationships (perceived superiority). Committed individuals are more likely to accommodate in conflicts and use constructive methods to solve problems (Rusbult & Buunk, 1993).

Yet, irrespective of their satisfaction, individuals are different in their need and interest for interdependence and how they view themselves in a relationship (Eidelson, 1983; Rusbult & Buunk, 1993; Cross & Madson, 1997). In relationships males tend to view themselves as more independent, due to independent self-construal (Cross & Madson,

1997). Their self-definition is based on their unique abilities (i.e. traits or values) and they make a sharper distinction between themselves and others (Cross & Madson, 1997). Self-esteem of males is enhanced when they perceive their uniqueness and higher competence in relation to others. Females see themselves more as interdependent in relationships, due to interdependent self-construal (Cross & Madson, 1997). Their self-definition is based on their relationships with others and they want connectedness and harmony with others (Cross & Madson, 1997). Their self-esteem rises when they receive positive feedback in caring and with more social skills. The social, institutional and cultural environment promotes development of independent self-construal in men and interdependence self-construal in women from a young age (Maccoby, 1990; Markus & Oyserman, 1989; Cross & Madson 1997). Parents for example speak more about emotions with their daughters than their sons (Cross & Madson, 1997). Males and females also have different gender roles. The way males and females view themselves influences their perception and behaviour (Cross & Madson 1997). For example, males have more emotions related to personal experiences; while females are more affected by emotions related to relationships with others. Females pay more attention to emotions compared to men and share their thoughts and feelings more easily with others (Cross & Madson, 1997). Instead, males favour shared activities instead of sharing emotions (Cross & Madson 1997). Compared to males, females are more vulnerable for depression and guilt when they believe they are not sensitive and concerning enough (Moran & Eckenrode, 1991; Baumeister, Stillwell & Heatherton, 1994).

Acitelli (2002) found that females were more satisfied with their relationship when they spend more time to communication about their relationship; though this was not found for males. For females this communication was associated with their well-being. Accitelli (2002) suggested that males find communication in their relationship important when they have to deal with problems. In contrast, women may feel that communication in their relationship is important to maintain a relationship and not only in dealing with problems. Hearing impairment has negative consequences for interactions with others (Hétu, Jones & Getty, 1993). This can have a negative impact on females in particular, as communication and relationships are more important for them (Cross & Madson, 1997). Wayner (1979) found that partners of patients with hearing impairment reported a reduction in interactions and were less satisfied with their relationship.

2.4 Support

2.4.1 Support of both partners as a way of coping with stress

Patients and their partners interact and share common experiences, concerns and emotional intimacy in relation to Menière's disease (Bodenmann, 2005). According to Berg and Upchurch (2007), a chronic disease like Menière can be perceived as a stressor which affects both partners. The patient is impaired due to the disease; yet both partners have to deal with the consequences of the disease (Stephens & Hétu, 1991). Both partners also have a higher risk of physical and psychological problems (Kuyper, 1993). Traditionally, studies have taken an individual perspective of stress and coping strategies in chronic disease (Lazarus & Folkman, 1984; Carver & Scheier, 1999). By contrast, recent studies have focused on a dyadic perspective, in how partners appraise stressors and engage in coping together (Bodenman, 2005). Coping is an interpersonal process in which both partners interact and support each other in a reciprocal way (Bodenmann, 2005). Support of partners is the most important source of support (Revenson, 1994). In a meta-analysis of thirteen studies, Bodenmann (2005), found that partner support explained 30% to 40% of the variance in relationship satisfaction. In healthy couples Papp & Witt (2010) found that positive and negative ways of support of partners contributed stronger to relationship satisfaction than individual ways of coping.

2.4.2 Two ways of support

Patients and partners can support each other with different attitudes, which can be co-operative, controlling or avoiding (Berg & Upchurch, 2007). In the literature two relevant ways of support are described. These ways are active engagement and protective buffering (Coyne & Smith, 1991, 1994; Buunk et al., 1996). Support through active engagement and protective buffering have been investigated in couples facing diseases such as cancer, myocardial infarction, diabetes and fibromyalgia (Hagedoorn et al., 2000; Coyne & Smith, 1991, 1994; Buunk et al., 1996; Schokker et al., 2010; Keers, Hagedoorn & Buunk, 2003).

Active engagement is described as: "involving each other in discussions, inquiring how one feels, asking about the help and information needed, and using other constructive problem-solving methods" (Buunk et al., 1996). This way of support is especially relevant for patients with Menière's disease and their partners, while communication is more difficult due to hearing loss and leads to misunderstandings and frustration (Hétu et al., 1993). Couples with hearing loss reported less intimacy in their communication and a reduced frequency of conversations (Hétu et al., 1993). It becomes harder to cope with chronic stressors and active

engagement can have a positive influence in this process (Buunk et al., 1996). Protective buffering is described by Buunk et al. (1996) as: “hiding one's concerns, denying one's worries, concealing discouraging information, preventing each other from thinking about the illness, and yielding in to avoid disagreement”. Protective buffering can have a negative impact, while avoiding communication can undermine intimacy in the long run.

2.4.3 Review of active engagement and protective buffering

We review the associations of support with relationship satisfaction, quality of life and gender separately for active engagement and protective buffering.

Active engagement (AE) has a positive influence on relationship satisfaction of patients and partners in general. The influence of active engagement is especially positive for women and individuals with a poorer quality of life. Patients with a myocardial infarction were more satisfied with their relationship when they perceived more active engagement (Buunk et al., 1996). In a study with diabetes patients, both partners were satisfied with their relationship when they used AE to support each other (Schokker et al., 2010). Furthermore, research with male and female cancer patients showed that the positive association between AE and relationship satisfaction was stronger when patients (especially females) reported more physical or psychological health problems (Hagedoorn et al., 2000). These patients with a poor quality of life were more satisfied with their relationship when they experienced more active engagement. Seeking social support was also associated with less disability of patients with tinnitus (Sullivan, Katon, Russo, Dobie & Sakai, 1994). This study showed that positive interaction with partners was particularly important for tinnitus patients with higher depression.

Related to gender, Badr (2004) found that the way of using AE is dependent on who is the patient. Both partners are less likely to use AE when the woman is ill than when the man is ill. However, it is possible that not all couples are comfortable with using AE. Both partners were satisfied if they were similar in level of AE, including lower levels of AE as well. In her study with diabetes patients, Schokker et al. (2010) found no gender differences. Nevertheless, the literature in general indicates that women benefit more from active engagement and similar support strategies (Hagedoorn et al., 2000; Keers et al., 2003; Kuyper, 1993).

Protective buffering (PB) is negatively associated with relationship satisfaction, especially under certain conditions like a low quality of life and low levels of active engagement. In a study of diabetes patients, Schokker et al. (2010) found that when both partners experienced a high level of PB in combination with a low level of AE, they were less satisfied with their relationship than couples who reported low PB. Both partners can perceive this type of negative support to be meant intentionally. The negative association of PB with

relationship satisfaction was also present when cancer patients had a worse quality of life (Hagedoorn et al., 2000). In comparison with cancer patients, (female) patients with fibromyalgia and their partners perceived more PB and lower levels of AE. This was related to more symptoms of depression (Keers et al., 2003).

Research has yielded different results regarding the association of support with relationship satisfaction. This relationship may also be affected by acceptance of disease. Acceptance was investigated in the current study and is reviewed in the next section.

2.5 Acceptance

2.5.1 The definition and role of acceptance

Acceptance is an intrapersonal process of adjustment to a disease, which diminishes the negative consequences of a disease (McCracken & Eccleston, 2003; Evers et al., 1998). Acceptance in general means a willingness to remain in contact with thoughts and feelings without having to follow or change them (Hayes & Wilson, 1994). Until now, no definitive medical solution for Menière's disease has been found and symptoms are difficult to influence (Van Cruijsen et al., 2006). This implies that patients and partners have to live with Menière's disease for the rest of their lives. Acceptance can be helpful for patients and partners to adjust to Menière's disease, since it means a disengagement from struggling with the disease (McCracken & Eccleston, 2003). Patients and partners give up unachievable goals, as they obtain more realistic expectations and engage in more positive activities.

According to McCracken and Eccleston (2003), acceptance of disease is different compared to the problem- or emotion focused coping developed by Lazarus and Folkman (1984). Especially problem-focused coping implies attempts to solve problems and control the consequences of a disease and this causes frustration if they are not effective (McCracken & Eccleston, 2003). Van Cruijsen et al. (2006) found that patients with Menière's disease used less task- or problem focused coping. Emotion-focused coping implies attempts to manage the emotions evoked by the event and is often used with health-problems (Vitaliano et al., 1990). In the long-term emotion-focused coping can lead to avoidance of the problem and more distress (McCracken & Eccleston, 2003). Acceptance of Menière's disease is realistic in developing feasible expectations and recognition of thoughts and feelings without changing them (McCracken & Eccleston, 2003; Hayes & Wilson, 1994). Different studies show that acceptance of a disease is associated with many positive outcomes in lives of patients and partners, like better health and psychological well-being, reduction of tension between partners, social support and relationship satisfaction (Scarinci et al., 2008; Kuyper, 1993; McCracken & Eccleston, 2003; Schutte, Noble, Malouff & Bhullar, 2009; Li & Moore, 1998).

Following this way, acceptance can foster support in couples who deal with Menière's disease. This implies that acceptance can be a mediating factor in the association between support and relationship satisfaction.

2.5.2 Acceptance in relation to Menière patients

The role of acceptance has been studied in patients suffering from chronic pain, chronic fatigue, hearing loss and tinnitus. In patients with chronic pain, higher acceptance was associated with less pain, disability and depression, improved work status and better mental health (McCracken & Eccleston, 2003; Viane et al., 2003). Research of acceptance on chronic fatigue showed that greater acceptance of chronic fatigue is related to less fatigue and more emotional stability and well-being. Acceptance contributed to this after controlling for demographic variables and fatigue severity (Van Damme, Crombez, Van Houdenhove, Mariman & Michielsen, 2006). Acceptance proved to be an important predictor of quality of life in a study with Menière patients; when patients reported higher acceptance they experienced a better quality of life (De Vries, 2011). As with chronic pain, it is not realistic to expect a complete reduction of tinnitus symptoms (Westin, Hayes & Andersson, 2008). This study showed that acceptance of tinnitus with engagement in activities mediated tinnitus distress, quality of life and depression seven months later. Another study in acceptance of tinnitus showed that higher acceptance of tinnitus leaded to less distress related to tinnitus (Schutte et al., 2009).

2.5.3 Acceptance in relation to partners of Menière patients

Acceptance of the disease is also important in case of the partner of the patient (Scarinci et al., 2008; Kuyper, 1993). It is easier for partners to accept and adapt to hearing impairment, when patients have accepted their impairment (Scarinci et al., 2008). This diminishes the impact of hearing impairment on the daily life of partners. Tension was reduced and partners showed a greater willingness to help, which made communication easier. The study of Kuyper (1993) showed that partners and patients could differ in their view how to deal and live with the disease, which could lead to arguments. Partners indicated that tension diminished when they accepted that patients had to find their own way to deal with the disease. They could not control the suffering of patients from their disease. When partners did not accept this, it leaded to feelings of frustration, depression and relational problems (Kuyper, 1993). Research indicates that acceptance contributes positively to quality of life, social support and relationship satisfaction. In this study the association of acceptance with relationship satisfaction is examined separately for patients and partners.

3. The current study

The current study was initiated by the Science Shop Medicine and Public Health of the UMCG (University Medical Centre Groningen) and the Committee Menière of the Dutch Association of Aurally handicapped people, NVVS in Dutch (Nederlandse Vereniging Voor Slechthorenden). The NVVS represents patients with hearing impairment in the Netherlands. With help of the Science Shop it is possible for patient organizations to conduct scientific research. The general question from the Committee Menière to the Science Shop of the UMCG was to investigate in what way Menière's disease influences the lives of patients and their partners within their relationship.

3.1 Investigated components of the support model

The components of the support model, relationship satisfaction, support (active engagement and protective buffering), quality of life and acceptance were investigated in patients with Menière's disease and their partners within a long-term relationship. For an overview of the research model see Figure 1.1. Menière's disease was defined along the definition of Menière Groningen, with the symptoms of vertigo attacks, tinnitus and hearing loss (Mateijsen, 2001). Relationship satisfaction is an evaluation of how satisfied both partners are with the quality and functioning of their relationship on a long term (Spanier, 1979). Active engagement is that couples actively share their thoughts and feelings and talk about problems. Protective buffering is that couple's avoid talking about problems and sharing thoughts and feelings (Buunk et al., 1996). Quality of life was described as a subjective evaluation of health and well-being in the functioning on several domains in life (Leventhal & Colman, 1997). Acceptance is a way of adjustment which diminishes the perceived negative consequences of a disease (Evers, et al., 1997).

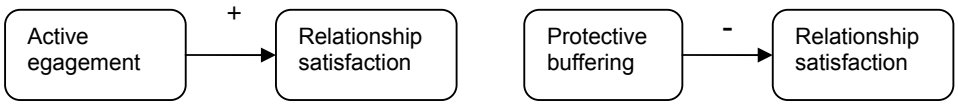
In the support model the association was investigated between ways of support and relationship satisfaction for both partners. A possible moderating factor of this association, quality of life, was examined as well. Acceptance as a mediating factor of this association was also investigated. Gender differences were taken into account.

3.2 Research questions and hypotheses

The central question in this study is how Menière's disease influences the lives of patients and their partners within their relationship. From the previously described literature and the central question the following three sub questions and four hypotheses were derived:

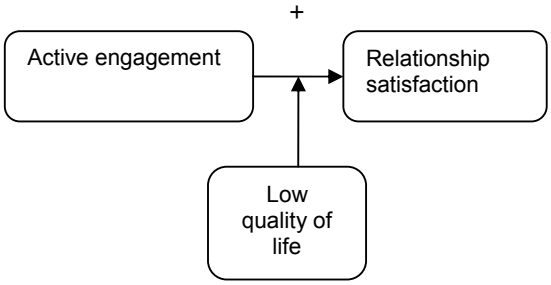
1. **What is the association between ways of support and relationship satisfaction for patients and partners?**

   1.1 The association of relationship satisfaction with active engagement is positive, while the association with protective buffering is negative for patients and partners.



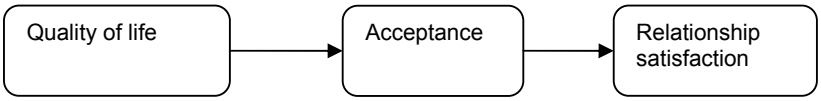
2. **Is the association between ways of support and relationship satisfaction moderated by quality of life for patients and partners?**

   2.1 The positive association between active engagement and relationship satisfaction is stronger when quality of life is low for patients and partners. This association is particularly stronger for female patients.

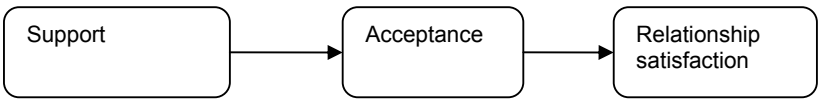


3. **Does acceptance play a mediating role in the associations of relationship satisfaction with quality of life and ways of support for patients and partners?**

   3.1 The association between quality of life and relationship satisfaction is mediated by acceptance of Menière's disease for patients and partners.



   3.2 The association between support and relationship satisfaction is mediated by acceptance of Menière's disease for patients and partners.



4. Method

4.1 Procedure

The research design was cross-sectional and was carried out by means of a questionnaire study (either via mail or internet). The protocol of this study was approved by the Medical Ethics Review Committee of the UMCG. In order to recruit participants for the research, a message was sent to a group of 510 Menière patients by the Committee Menière of the NVVS. The group of Menière patients were registered by the NVVS, for they had participated in a study conducted by the Science shop and the NVVS in 2010 (De Vries, 2011). The message contained information about the present research project and asked the patients to participate with their partners and to inform the NVVS if they were not willing to do so.

After the message which informed the participants, the questionnaires were sent by mail or email. The sending was done by the NVVS. The researchers did not have access to personal information of participants. The Menière patients, who were approached by mail, received two questionnaires, one for themselves and one for their partner. Patients and partners each returned the questionnaire in a separate prepaid envelope. The patients approached by e-mail were requested to forward the link to the questionnaire to their partners. Before responding to the questions, the participants, both patients and partners, were to read an introduction that described the nature of the study, the duration, the guarantee of anonymity and the voluntary participation in the research. The introduction explained also that participating couples received each a personal code to connect them in the analysis. The patients and the partners were requested in the introduction to fill out the questionnaires independently. The participants had one month to fill out the questionnaires and after two weeks a reminder was sent. The researchers received the anonymous questionnaires and were the only individuals who had access to these data.

4.2 Response

At the start a message was sent by the NVVS to a group of 510 Menière patients which provided information about the research project and the possibility to withdraw from the study. A number of 42 patients responded to this message. The main reason for their withdrawal was that they did not have a partner. Secondly, the questionnaire was sent to 468 patients. In advance 140 patients had indicated that their partners also wanted to participate in the study. In Figure 4.1, a flow-chart is presented of the total group of participants who filled out the questionnaires and the participants who were included in the analysis. The sample

consisted of patients who were diagnosed with Menière's disease and their partners. Approximately 82% of the approached patients had a long-term relationship, whereof the majority (90.8%) was married (De Vries, 2011). Couples with a long-term relationship could be married, cohabiting or living apart. Only the connected couples with the same participant number were included in the analysis. In total 142 connected couples were included in the analysis (284 participants). The estimated response rate was 37%, we based this figure on 142 couples in the analysis and an estimated figure of 384 couples who received the questionnaire (based on the 82% of 468 patients having a relationship). A number of 138 couples were heterosexual oriented and 4 couples were homosexually oriented (two couples consisted of females and two were male couples). There was one couple where both partners had Menière's disease. The participants who did not complete the questionnaire were excluded from the sample as well as participants who did not have a partner.

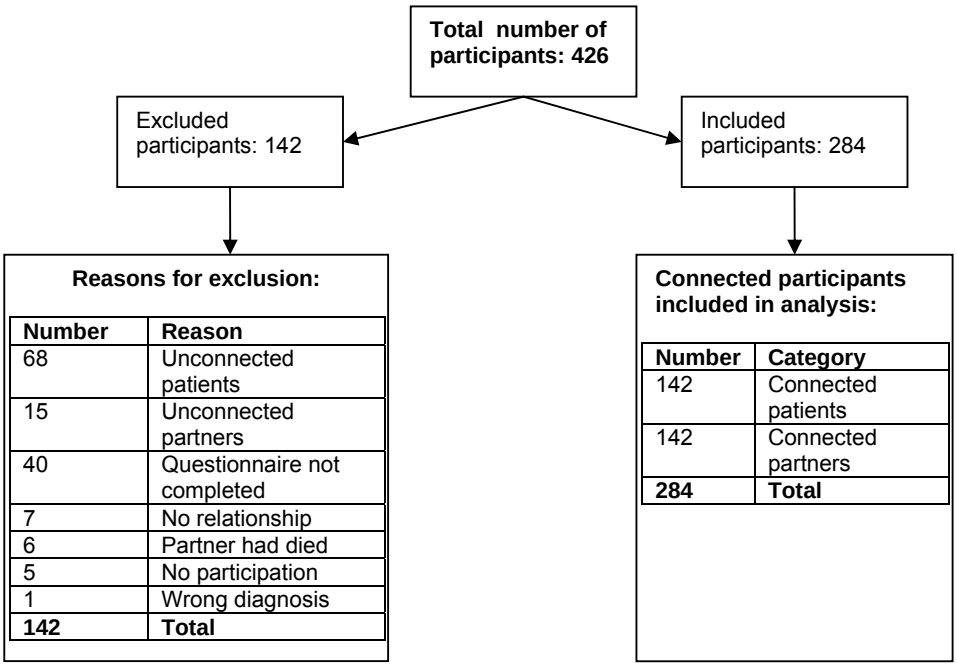


Figure 4.1. Overview of included and excluded participants

Between the groups of connected and unconnected participants there were no significant differences on the characteristics age, education and workforce status. Neither there were differences on the variables: relationship satisfaction, acceptance, quality of life variables and protective buffering. The only significant difference was discovered in active engagement. Connected patients reported a higher mean score on AE (19.14, SD = 3.88) than unconnected patients (17.93, SD = 4.56), (independent t test, t (209) = 2.01, $p = .046$). Connected partners too, reported higher AE (18.48, SD = 3.34) than unconnected partners (15.07, SD = 4.95), (independent t test, t (154) = 3.47, $p = .001$).

4.3 Questionnaire and variables

The questionnaire consisted of scales which were the same for both partners and slightly different scales for patients and partners, see appendix 4. We measured the following components with existing scales: relationship satisfaction, active engagement and protective buffering, quality of life and acceptance. An overview of the components is presented in table 4.1. A statistical measurement of internal reliability is Cronbach's alpha which ranges from 0 (unreliable) to 1 (very reliable) and can be computed within SPSS. The components showed all a good reliability, except for protective buffering, this was sufficient.

Table 4.1 Overview of variables, subscales, range and Chronbach's alpha

Variable	Subscale	Range	Alpha
Relationship-satisfaction	Marital quality (MMQ)	0-8	.897
Support	Active engagement (APO) patients	5-25	.886
	partners		.822
	Protective buffering (APO) patients	7-32	.635
	partners		.693
Quality of life			
Anxiety	Anxiety (HADS)	0-21	.895
Depression	Depression (HADS)	0-21	.838
Social functioning	Social functioning (RAND-36)	0-100	.849
Physical Role	Physical role limitations (RAND-36)	0-100	.885
Emotional Role	Emotional role limitations (RAND-36)	0-100	.877
Vitality	Vitality (RAND-36)	0-100	.886
Acceptance	Acceptance (ICQ) patients	6-24	.936
	partners	6-24	.931

The following responses were collected with self-constructed items: socio-demographic characteristics, specific questions for Menière's disease, and exploring questions for the NVVS. The different components are described in detail below, including Cronbach's alpha and the test- retest reliability. This is a correlation coefficient (ranging from 0 to 1) indicating the degree of similarity when a questionnaire is filled out on two different points in time.

1. Relationship satisfaction: The Maudsley Marital Questionnaire (MMQ). The MMQ measures marital quality (Arindell et al., 1983). The subscale 'adjustment in marital life' (10 items) was used to measure relationship satisfaction in this study. The questions are answered on a 9-point Likert scale. Originally a lower score indicates higher satisfaction. However, the items in this study were recoded to simplify the interpretation of results (Schokker et al., 2010; Hagedoorn et al., 2000). A higher mean score indicates higher

relationship satisfaction, (range 0-8). An example of a question is: 'Is your partner attractive to you as a person?' Cronbach's alpha ranged from 84 - .89 in normal and distressed couples and the test-retest reliability was .81 - .86 (Arindell et al., 1983).

2. Support: Active engagement, Protective buffering and Overprotection (APO).

The APO measures three ways of support (Buunk et al., 1996; Coyne & Smith, 1990, 1994). Active engagement (5 items) and protective buffering (8 items) were used in this study. The answers are rated on a 5-point Likert scale. This questionnaire consisted originally of two versions. The patient's version indicated the perceived support from the partner. The partner's version indicated the support offered to the patient. Two examples of questions are: 'My partner tries to discuss my illness with me openly (AE)' and 'My partner tries to hide his or her worries from me (PB)'. Values of Cronbach's alpha (Buunk et al., 1996) were for patients: .80 (AE) and .79 (PB). For partners: .70 (AE) and .75 (PB). Values of test-retest reliability were for patients: .55 (AE) and .70 (PB). For partners: .57 (AE) and .69 (PB). For this study, we made a small modification in the instructions to make the questionnaire suitable for the way the partner is supported and consisted also of two versions (partner and patient). The second item of the questionnaire (following doctor's instructions from the PB scale) was excluded from the analysis for the item did not fit into the situation of partners. Cronbach's alpha for PB only slightly diminished from .640 to .635.

3. Quality of life: Hospital Anxiety & Depression Scale (HADS). The HADS is developed by Zigmond and Snaith (1983) and measures anxiety and depression by self-report (both subscales 7 items). The questions are answered on a 4-point Likert-scale and both scales range from 0 to 21. A score from 0 to 7 means no indication for anxiety or depression, 8 to 10 is a likely indication and 11 or higher is a strong indication (Zigmund & Snaith, 1983). Cronbach's alpha was examined in Dutch populations (including health problems). Anxiety ranged from .81 to .84 and depression ranged from .71-.86 (Spinhoven et al., 1997).

4. Quality of life: RAND-36. The Rand-36 measures health related quality of life (Van der Zee & Sanderman, 1993). The following 4 subscales of the Rand-36 were used: physical role limitations (4 items), emotional role limitations (3 items), social functioning (2 items), vitality (4 items). The scores of each subscale ranged from 0 to 100-points. A higher score indicates a better quality of life. An example is: 'How often did you feel tired during the last four weeks?' Cronbach's alpha ranged from .71 - .90 in the four subscales and the test-retest reliability ranged from .58 - .76 (Van der Zee & Sanderman, 1993).

5. Acceptance: Illness Cognition Questionnaire (ICQ). The ICQ measures three illness cognitions (Evers et al., 1998), including the subscale about acceptance used in this study. The subscale has 6 items on a 4-point Likert scale indicating the degree of agreement. A higher average score indicates a higher level of acceptance (range total score 6-24). An example is: I have learned to live with my illness. Chronbach's alpha was .90 in patients

with rheumatoid arthritis (RA) and .91 in patients with Multiple Sclerosis (MS) and test-retest reliability was .76 in patients with RA and .78 in patients with MS (Evers et al., 1998). In this study, we changed the word 'illness' in the items in 'Menière's disease' for patients, and 'Menière's disease of my partner' for partners.

6. Socio-demographic Characteristics and questions about Menière's disease. The following socio-demographic characteristics were collected for patients and partners: date of birth, gender, marital status, relationship type, duration of relationship, education-level, co-morbidities and workforce status. The questions about MD were answered by patients only: duration of MD, diagnosis and symptoms in years, severity of symptoms and the specialist who diagnosed the patient with MD: an ENT specialist (which means an ear, nose, and throat specialist), another medical specialist, self diagnosis or otherwise.

7. Exploring questions for NVVS. Some exploring questions were added for the purpose of the NVVS. They were excluded from this study and will be analyzed in a follow-up study. The questions were about global quality of life and relationship satisfaction with MD and without MD (rated on scale from 1-10), problems with activities and communication, support from network, change in (sexual) relationship, need for information and contact. Open questions were about consequences of MD in lives of partners and possible suggestions for other couples.

4.4 Data analysis

4.4.1 Missing responses and descriptive statistics

We excluded non-completed questionnaires from the analysis. There were also sub-scales with some missing responses, while it was necessary to have complete total scores. We calculated with the computer program 'Mistel' if missing data could be replaced (within the UMCG this program was developed by Dr. E. van Sonderen). The maximum number of replaced items was based on Cronbach's alpha and the number of items. When the maximum was not exceeded, the data were replaced with the mean score of the participant. The replaced data ranged from one to three items and one to five participants per subscale.

The statistical analysis was conducted with the computer program SPSS-16. The significance of the results was based on an alpha of .05. Descriptive statistics (frequencies, percentages and mean scores on variables) were computed to describe the groups of patients and partners. Correlation coefficients were calculated between the variables of the model, socio demographic variables and disease characteristics. Independent t-tests were conducted to compare different mean scores on variables between partners and patients.

4.4.2 Multiple regression analyses

We tested the hypotheses with the enter-method of hierarchical multiple regression analysis. Per hypothesis two different regression models were analyzed, to compare the groups of patients and partners. When it was needed groups were further divided by gender. In the analysis we controlled for the influence of disease characteristics and socio-demographic variables to see if the associations remained significant.

For hypothesis 1.1, regression analyses were conducted to test the associations between support and relationship satisfaction. We conducted a moderation regression analysis for hypothesis 2.1, to test the moderating relationship of quality of life between support and relationship satisfaction. Firstly, hierarchical regression analyses were conducted to examine a general moderating effect. Secondly, we made graphs of the moderating effects to examine the influence of high and low quality of life into detail. The dependent and independent variables were standardized with a mean score of 0 and a standard deviation of 1 to simplify interpretation of results (Siero, Huisman & Kiers, 2009). The patients and partners were divided in high and low quality of life along the median score.

For hypothesis 3.1 and 3.2 we tested a mediating association for acceptance. We used the causal step analysis of Baron and Kenny (1986). Firstly, the predictor variable was entered. Secondly, acceptance was added as mediating variable. After this, we tested the mediating role of acceptance with the Sobel test, as proposed by Baron and Kenny (1986) and the bootstrap method (Shrout & Bolger, 2002). The bootstrap method is more powerful than the Sobel test, while it does not require a normal distribution (Shrout & Bolger, 2002; Mallinckrodt, Abraham, Wei & Russell, 2006). The bootstrap method estimates the mediating effect more accurately by random sampling over populations. In this study the mediating effect was computed over 10.000 samples (Mallinckrodt et al., 2006).

The assumptions related to multiple regression analysis were checked and showed that there is no violation present. We checked for multicollinearity between the variables. The associations were not too high, while the values of the Variance Inflation Factor were below 4. Tolerance values were reasonably above 0, (Siero, Huisman & Kiers, 2009). There were no unusual cases of outliers to be reported. Values of Cook's distances were below 1 (Siero, Huisman & Kiers, 2009). There was no violation of normality, while normal P-P plots showed that the residuals are reasonably distributed on a straight diagonal line from bottom left to top right. The scatter plot showed that the standardized residuals were randomly divided around zero, which indicated a linear relationship of variables with relationship satisfaction. There was a constant pattern of the variance in testing for homoscedasticity. The residuals were independent while there was no systematic association to be seen in the scatter plot of the standardized residuals.

5. Results

5.1 General characteristics of patients and partners

We started to present the results with a description of the participants. The sample is divided in two groups, the patients and the partners. When appropriate, these groups are further divided by gender. In table 5.1 an overview is presented for patients and partners on socio-demographic variables.

Table 5.1. Overview of patients and partners on socio-demographic variables
(gender, age, marital status, co-morbidities, education level and workforce status).

	Patients (N = 142)		**Partners** (N = 142)	
	N	%	N	%
Gender				
Male	64	45.1%	78	54.9%
Female	78	54.9%	64	45.1%
Age in years				
32 – 45	11	7.7%	14	9.9%
46 – 65	90	63.4%	84	59.2%
66 and older	41	28.9%	44	31.0%
Mean age years (SD)	60	(10.4)	60	(10.4)
Marital status				
Married	128	90.0%	128	90.0%
Cohabiting	10	7.0%	10	7.0%
Non-cohabiting	4	3.0%	4	3.0%
Co-morbidities				
Yes	78	54.9%	55	38.7%
No	64	45.1%	87	61.3%
Education level				
Low	24	16.9%	25	17.6%
Middle	64	45.1%	57	40.1%
High	54	38.0%	60	42.3%
Workforce status				
Employed	48	33.8%	63	44.4%
Disabled	27	19.0%	6	4.2%
Retired	47	33.1%	58	40.8%
Others	20	14.1%	15	10.6%

In the group of patients 45.1% is male and 54.9% is female. The mean age of patients and partners is 60 years and the majority of the sample is between 46 and 65 years old. The majority of the couples were married (90%) and the mean duration of their relationship is 33.82 years (SD = 12.92). In both groups the majority had a middle or high level of education. When we looked at workforce status, one out of three patients was

employed and one out of five patients was disabled. Almost the half of the partners is employed and only a small part is disabled. A relatively large part of both groups is retired. Of the patients, 54.9% was also diagnosed with another chronic illness, compared to 38.7% of the partners. An overview of these co-morbidities is presented in appendix 1, figure 1.

We continue with an overview of the characteristics of Menière's disease in table 5.2. On average, patients experienced the symptoms of MD for duration of 13 years and this was also the mean time from the diagnosis with MD. Patients rated hearing loss and tinnitus as more severe on a scale of 1 to 10 than vertigo attacks.

Table 5.2. Diagnosis, duration and severity of symptoms related to Menière's disease.

	Length (years)		**Severity**	
	Mean (SD)	*Range*	*Mean (SD)*	*Range*
Diagnosis with MD	13.39 (9.11)	1-40	-	-
Vertigo	14.09 (10.60)	0-50	3.80 (2.51)	0-10
Tinnitus	13.25 (10.49)	0-58	5.74 (2.44)	0-10
Hearing loss	13.38 (9.63)	0-40	6.34 (2.54)	0-10

Other characteristics of MD are shown in table 5.3. The majority of the patients received the diagnosis of MD from an ENT (Ear, Nose and Throat) specialist, while a minority received a diagnosis from another medical specialist or was diagnosed otherwise. Half of the patients experienced tinnitus and hearing loss in one ear and around one third of the patients reported hearing loss and tinnitus in two ears. In a small part of the group tinnitus and hearing loss were not present. A quarter of the patients had no problems with vertigo.

Table 5.3. Other characteristics of Menière's Disease (way of diagnosis, affected ears with hearing loss and tinnitus and no problems with vertigo)

Patients (N=142)	%		%
Diagnosis		**Hearing loss and tinnitus**	
ENT-specialist	85.9	One ear	54.2
Other Medical specialist	10.5	Two ears	37.0
Other	3.5	Not applicable	8.8
		No vertigo problems	25.4

5.1.1 Characteristics of relationship satisfaction and other variables

We conducted a descriptive analysis to examine the influence of the components in the support model on relationship satisfaction. Average scores on relationship satisfaction, acceptance and quality of life are presented in table 5.4 for patients and partners. Independent t-tests indicated if differences were significant.

Table 5.4. Overview (mean scores, standard deviations and range) of relationship satisfaction, acceptance and quality of life (defined in 6 variables).

	Patients			Partners		
	Mean	*(SD)*	*Range*	*Mean*	*(SD)*	*Range*
Relationship satisfaction	**6.89**	**(1.00)**	**3-8**	**6.90**	**(1.02)**	**3-8**
Male	7.10	(0.89)**		6.83	(1.04)	
Female	6.71	(1.06)**		6.99	(0.99)	
Acceptance	**16.73**	**(4.02)***	**6-24**	**18.92**	**(3.23)***	**11-24**
Male	17.56	(3.62)**		18.78	(3.22)	
Female	16.05	(4.22)**		19.09	(3.26)	
Quality of life						
Anxiety	6.46	(4.32)*	0-21	4.53	(3.89)*	0-17
Depression	5.75	(3.98)*	0-16	3.57	(3.29)*	0-13
Vitality	50.21	(20.04)*	0-100	65.39	(18.31)*	0-100
Social functioning	58.19	(25.31)*	0-100	79.75	(22.66)*	0-100
Physical Role limitations	40.85	(39.55)*	0-100	76.94	(36.72)*	0-100
Emotional Role limitations	61.97	(42.50)*	0-100	88.26	(29.23)*	0-100

Patients N = 142, male N = 64, female N = 78. Partners, N = 142, male N = 78, female, N = 64.
*. Independent t-test patients and partners, $p < .001$. ($t = -7.969$ to 5.036, $p = .000$ to $.884$).
**. Independent t-test male and female patients, $p < .05$. ($t = -.002$ to 2.321, $p = .023$ to $.998$).
A higher score indicates more relationship satisfaction and acceptance, more symptoms of anxiety and depression (a poorer quality of life). Yet a higher score indicates a better quality of life for vitality, social functioning, physical- and emotional role limitations.

Relationship satisfaction. Patients and partners were equally satisfied with their relationship. However, male patients were more satisfied with their relationship than female patients (see figure 5.1), which was a small difference. Overall, patients and partners were quite satisfied with their relationship. The average scores were only one point below the maximum score.

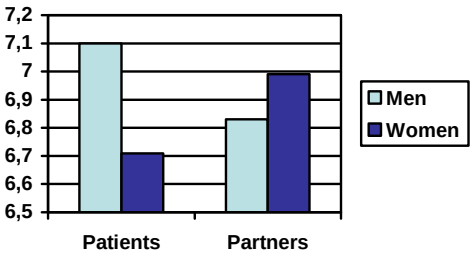


Figure 5.1. Relationship satisfaction (mean scores) of patients and partners divided by gender.

Acceptance. Patients and partners differed in the extent to which they accepted MD. Patients accepted their own disease to a lesser extent compared to partners, who showed a higher acceptance of MD. Male patients showed higher acceptance than female patients.

Quality of life. Quality of life was measured with six variables. A poorer quality of life was indicated by a higher score on anxiety and depression and a lower score on vitality, social functioning, physical- and emotional role limitations. Overall, patients experienced a poorer quality of life than partners. In all scales these differences were significant. There were no differences between gender within the groups of patients and partners.

Indication for anxiety and depression. According to the HADS, participants can be quantified with no indication, a likely indication or a strong indication for anxiety or depression. In table 5.5 we presented the percentages of symptom indications. Significantly more patients than partners showed a likely or strong indication for anxiety and depression. Of the patients 38.7% reported a likely or strong indication for anxiety compared to 16.2% of the partners. For depression 33.8% of the patients and 11.9% of the partners showed a likely or strong indication for symptoms.

Table 5.5. Indication for anxiety and depression (percentages).

	Anxiety*		**Depression***	
	% Patients	% Partners	% Patients	% Partners
No symptoms	61.3	83.8	66.2	88.0
Likely symptoms	17.6	7.7	20.4	6.3
Strong symptoms	21.1	8.5	13.4	5.6

* Significant difference between patients and partners for anxiety ($\chi^2(2) = 18.13$, $p < .001$) and depression ($\chi^2(2) = 19.40$, $p < .001$, df 2).

Support. We compared support for patients and partners. Patients perceived support from their partners through AE and PB. For example, patients perceived that their partners were generally willing to talk about MD-related problems. The partners also perceived support from the patient through AE or PB. The results of support are presented in table 5.6. Independent t-tests compared support within the groups of patients and partners.

Table 5.6. Mean scores, standard deviations and range of the variables of AE and PB.

	Patients			**Partners**		
	Mean	*(SD)*	*Range*	*Mean*	*(SD)*	*Range*
Active engagement	**19.14**	**(3.88)**	**8-25**	**18.49**	**(3.34)**	**9-25**
Male patients – Female partners	20.03	(3.35)*		18.38	(3.38)	
Female patients – Male partners	18.41	(4.14)*		18.58	(3.34)	
Protective buffering	**17.61**	**(4.22)**	**8-32**	**18.00**	**(4.17)**	**8-26**
Male patients – Female partners	16.36	(3.76)*		18.66	(3.70)	
Female patients – Male partners	18.63	(4.33)*		17.46	(4.48)	

Patients, N = 142, male N = 64, female N = 78. Partners, N = 142, male N = 78, female N = 64.
* Independent t-tests between male and female patients, $p < .01$. ($t = -3.29$ to 2.52, $p = .001$ to $.722$).

Active engagement. Especially female patients perceived their partners to be less supportive through active engagement compared to male patients. Female patients reported an average score on AE of 18.41, while male patients reported 20.03. Overall, patients perceived more AE, while partners perceived slightly less AE.

Protective buffering. Especially male patients perceived less protective buffering compared to female patients. The average reported PB of male patients was 16.36, while female patients reported 18.63. Patients in general perceived slightly less PB than partners.

5.1.2 Associations with relationship satisfaction

In the last part of the descriptive analysis we investigated the associations between relationship satisfaction and the variables support, quality of life and acceptance. Correlation coefficients were computed for patients and partners. After this, coefficients were computed for gender in both groups. We presented the results in table 5.7.

Table 5.7. Correlation coefficents of relationship satisfaction with the independent variables

Relation satis faction	Accep tance	Anxiety	Depres sion	So cial	Physi cal role	Emo tional role	Vita lity	AE	PB
Patients	.377**	-.261**	-.297**	.264**	.164	.226**	.218**	.643**	-.318**
Partners	.471**	-.311**	-.485**	.269**	.181*	.181*	.156	.636**	-.198*
Male patients	.348**	-.356**	-.318**	.193	.124	.341**	.124	.533**	-.323**
Female Patients	.357**	-.181	-.287*	.310**	.155	.126	.290**	.680**	-.257*
Male Partners	**.667****	-.385**	-.510**	.315**	**.385***	.166	**.295****	.631**	**-.287***
Female partners	**.222**	-.199	-.451**	.224	**-.044**	.191	**-.055**	.654**	**-.098**

Patients, N = 142, male N = 64, female N = 78. Partners, N = 142, male N = 78, female N = 64. Significance correlation: *. p < 0.05 (two-tailed), **. p < 0.01. Bold coefficients indicate significant differences (Fisher Z test) in male and female partners, p < .05.

For patients, the highest positive associations with relationship satisfaction were perceived AE (.643) and acceptance (.377). This implied that patients were more satisfied with their relationship when they perceived more AE and higher acceptance of MD. When patients reported better social functioning, fewer emotional role limitations and higher vitality, their relationship satisfaction was also higher. Patients were less satisfied with their relationship when they reported more PB and higher anxiety and depression.

Partners too, were more satisfied with their relationship when they perceived more AE (.636) and when they accepted MD to a higher extent (.471). Relationship satisfaction of partners was also higher when they reported better social functioning and fewer physical

and emotional role limitations. Partners were less satisfied with their relationship when they reported more PB, anxiety and depression. We examined significant differences (according to the Fisher Z test) in correlation coefficients for male and female partners. Male partners in particular were more satisfied with their relationship when they reported more acceptance of MD, fewer physical role limitations and better vitality. For female partners these factors had no influence on their relationship satisfaction. Male patients reported lower relationship satisfaction with more anxiety and emotional role limitations.

We investigated associations of demographic variables and disease characteristics with the other variables. More detailed information can be found in the appendix 1, tables 1 to 3. With regard to patients, the factors severity of vertigo, tinnitus and hearing loss, education level and age (years) showed significant associations with other variables. Partner's education level, workforce status, age and co-morbidities showed significant associations. For this reason, the influence of these characteristics was controlled for in the analyses.

At the end of the descriptive analysis we can summarize the following:

- Female patients were slightly less satisfied with their relationship than male patients.
- Patients reported fewer acceptance and a poorer quality of life compared to partners.
- Female patients were more likely to report lower levels of active engagement, whereas male patients were more likely to report lower levels of protective buffering.
- Relationship satisfaction of patients and partners was higher when they experienced more active engagement and higher acceptance of MD.
- Relationship satisfaction was lower when patients and partners reported more protective buffering, anxiety and depression.

5.2 Question 1: Support and relationship satisfaction

We examined the associations with relationship satisfaction more closely to provide an answer to the research questions and to ascertain whether the results supported our hypotheses. The first research question and the derived hypothesis examined support:

1. *What is the association between support and relationship satisfaction for patients and partners?*

Hypothesis 1.1: The influence of active engagement is positive on relationship satisfaction of patients and partners, while protective buffering has a negative influence.

Patients and partners were more satisfied with their relationship when they perceived more active engagement. The results presented in table 5.8 supported the hypothesis. Female patients in particular reported higher relationship satisfaction when they perceived more active engagement. In female patients, active engagement explained 46.3% of the variance in relationship satisfaction, while active engagement had less influence on male patients. The effect of active engagement remained significant when we controlled for demographic variables and disease characteristics (ß AE = .631 to .680). The symbol ß stand for beta weight and ranges generally from 0 to 1. A beta weight indicates the relative impact of a variable in comparison with other variables in a regression analysis.

Table 5.8. Regression analysis for patients and partners divided by gender. Predictor variable is perceived support (AE and PB). Dependent variable is relationship satisfaction.

	Patients		**Partners**	
	ß	R^2	ß	R^2
Active Engagement				
Male	.533	.285***	.631	.398***
Female	.680	.463***	.654	.428***
Protective buffering				
Male	-.323	.104**	-.287	.083*
Female	-.257	.066*	-.098	.010

Patients, N = 142, male N = 64, female N = 78. Partners, N = 142, male N = 78, female N = 64.
Significance t-value and R^2: *. p < 0.05, **. p < 0.01, ***. p <.001. (ß AE: t = 4.97 to 9.92, p < .001).
(ß PB: t = -.778 to -3.967, p = .001 to .440).

The results in table 5.8 showed a small negative association of protective buffering with relationship satisfaction. This implied that when patients and partners perceived more protective buffering, they were slightly less satisfied with their relationship. Male patients and male partners in particular were less satisfied with their relationship when they perceived more protective buffering. Protective buffering had no influence at all on female partners. The small effect of protective buffering remained significant (except female partners) after controlling for the influence of demographic variables and disease characteristics (ß PB = -.098 to -.313).

In sum, active engagement had a strong and positive influence on relationship satisfaction of patients and partners. Particularly female patients benefited from active engagement. Protective buffering had a slightly negative influence on relationship satisfaction, in particular on male patients and male partners.

5.3 Question 2: Quality of life, support and relationship satisfaction.

The association between support and relationship satisfaction is taken a step further, as the influence of quality of life on this association is taken into account.
The second research question and the derived hypothesis were:

2. Is the association between support and relationship satisfaction moderated by quality of life for patients and partners?

Hypothesis 2.2: The positive association between active engagement and relationship satisfaction is stronger with a poor quality of life for partners and patients (in particular for female patients).

We conducted a moderation regression analysis to test the association that the positive influence of active engagement on relationship satisfaction was stronger with a poorer quality of life. Quality of life was defined by six variables. A moderating relationship means that the association between active engagement and relationship satisfaction changes with high or low levels of quality of life. Firstly, we examined if there was a general influence of quality of life on the association. Secondly, we made graphs to examine the influence of high and low quality of life into detail. The results presented in table 5.9 showed the general influence of quality of life. The variance of the first step (R^2 Step 1) showed the influence of both variables (AE and a quality of life component) on relationship satisfaction. A significant change in the variance of the second step (Change R^2 Step 2) showed if the product of AE and a quality of life component added more unique variance. This indicates a general moderating influence of quality of life.

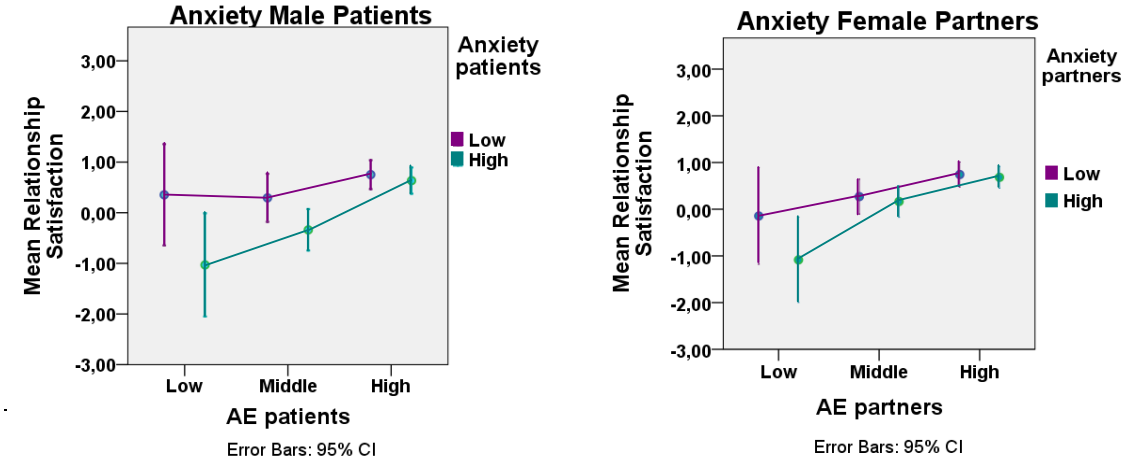
An interesting pattern surfaced in male patients and their female partners. For male patients and female partners, anxiety, depression and emotional role limitations showed a general influence on the association between active engagement and relationship satisfaction. These variables are related to the psychological aspect of quality of life. Social functioning showed a general influence for female partners only. When we controlled for the influence of demographic variables and disease characteristics all moderation effects for patients remained significant (b = -.246 to .272). For partners, there was no significant influence from demographic variables.

Table 5.9. Explained variance of moderation regression analysis for patients and partners divided by gender. Predictor variable is perceived AE and moderator variable is quality of life. Dependent variable is relationship satisfaction.

		Patients R^2 Step 1	Change R^2 Step 2	Partners R^2 Step 1	Change R^2 Step 2
Anxiety	Male patient – Female partner	.423	.073*	.489	.079*
	Female patient – Male partner	.477	.022	.456	.003
Depres-ion	Male patient – Female partner	.429	.059*	.559	.084*
	Female patient – Male partner	.505	.001	.493	.005
Social	Male patient – Female partner	.380	.004	.462	.082*
	Female patient – Male partner	.498	.005	.465	.009
Physical	Male patient – Female partner	.345	.013	.431	.001
	Female patient – Male partner	.467	.021	.461	.002
Emotion	Male patient – Female partner	.379	.056*	.476	.064*
	Female patient – Male partner	.479	.003	.414	.005
Vitality	Male patient – Female partner	.383	.001	.433	.000
	Female patient – Male partner	.520	.000	.434	.000

Patients, N = 142, male N = 64, female N = 78. *. The variance added in Change R^2 step 2 is significant at the < .05 level. Significant moderation effects for patients (b = -.268 to .302, t = -2.43 to 2.95, p = .005 to .028) and for partners (b = -.308 to .322, t = -3.28 to 3.76, p = .001 to .005)

In the second step, we examined the association of active engagement with relationship satisfaction influenced by quality of life. We made graphs for male patients and female partners which are presented in Figure 5.2. The X-axis represents the level of active engagement (low, middle and high) and the Y-axis indicates relationship satisfaction. The green lines for anxiety and depression indicated relationship satisfaction for a poor quality of life and the violet lines for a better quality of life. For emotional role limitations and social functioning (female partners only) the green lines indicate relationship satisfaction with a better quality of life. The vertical lines represented the 95% confidence intervals. For an overview of the distribution of participants per variable see appendix 1, table 4.



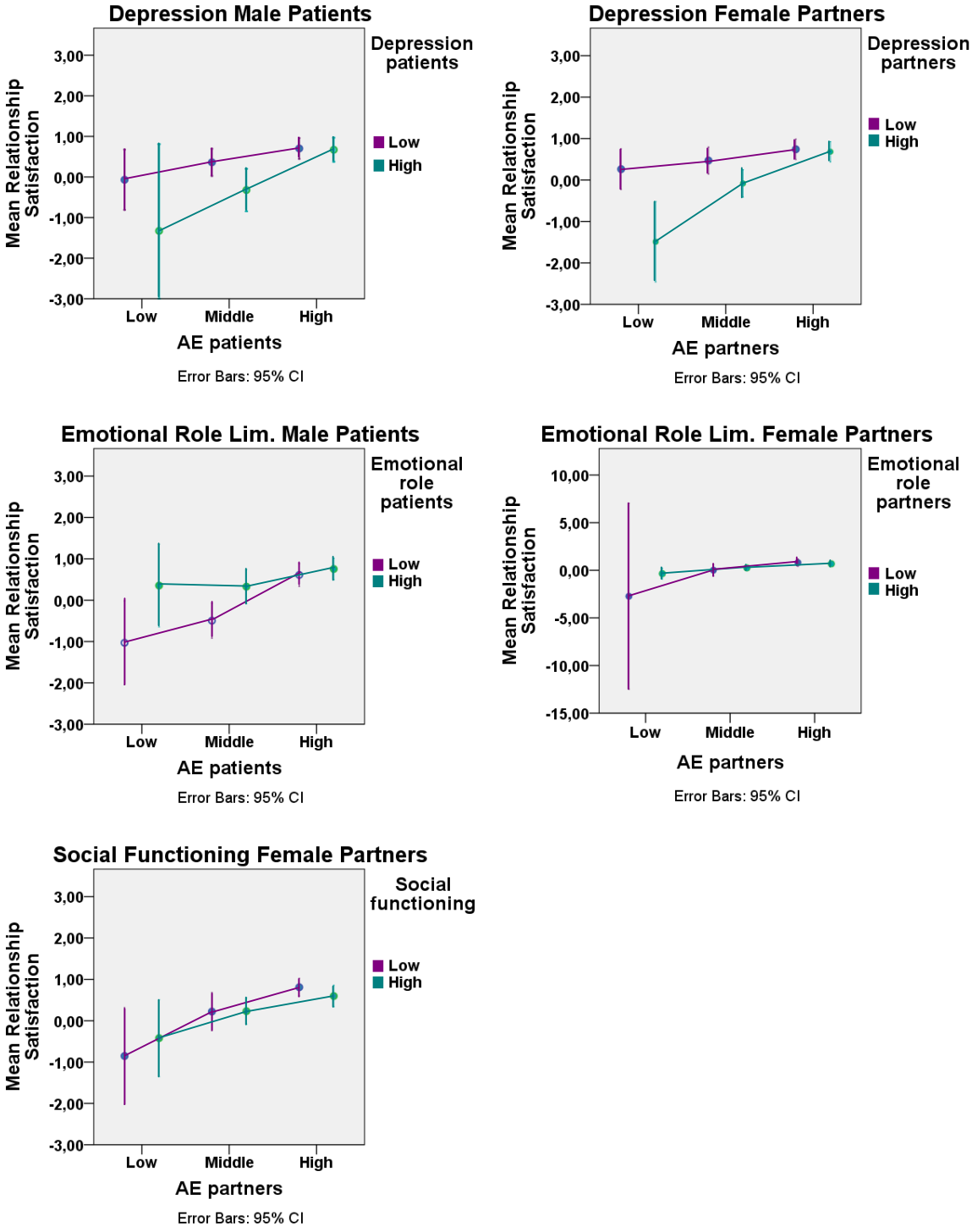


Figure 5.2. Impact of quality of life on active engagement and relationship satisfaction.

In Figure 5.2, we see that male patients and female partners with high anxiety and depression (and low emotional role limitations for male patients) were less satisfied with their relationship when they perceived less active engagement. Their satisfaction was

higher with more perceived AE (process indicated by a steeper green line). Male patients and female partners with lower anxiety and depression were more satisfied with their relationship overall, and this was less dependent on AE (indicated by the flatter violet line). Overall, male patients and female partners reported higher relationship satisfaction when they perceived more AE. In that case there were no longer differences in relationship satisfaction between low or high quality of life. For male patients and female partners the impact of a poorer quality of life was the strongest for anxiety, depression and emotional role limitations (only male patients). The 95% confidence intervals showed also the strongest differences from each other. For female partners there seemed to be no moderating effects for social functioning and emotional role limitations. There were very few female partners with low emotional role limitations.

Finally, we examined the influence of quality of life on active engagement (female patients only) and protective buffering. For female patients in particular we expected a general influence of quality of life, see table 5.9. However, none of the moderating effects was significant. The association between active engagement and relationship satisfaction did not change with high or low quality of life. More detailed results are presented in appendix 1 table 5. These results showed that female patients reported higher relationship satisfaction when they perceived more AE (ß (AE) = .645 to .681, total R^2 = 46.7 to 52%) in all quality of life conditions. The impact of active engagement was stronger than depression, social functioning and vitality (beta weights of AE were three times stronger).

The association of protective buffering with relationship satisfaction did not change with high or low levels of quality of life; none of the moderating effects of quality of life was significant. We therefore explored the main impact of PB and quality of life. In appendix 1 table 6 these results are shown. When patients perceived more PB they were less satisfied with their relationship. The negative impact of PB was stronger than a poor quality of life, which had also a negative influence on relationship satisfaction (R^2 = 11.2 to 16.1%). When partners reported more anxiety, depression or poorer social functioning, they were less satisfied with their relationship (R^2 = 9.6% to 24.2%). Protective buffering, physical- and emotional role limitations and vitality had no influence on relationship satisfaction of partners.

In sum, the results provided partial support for hypothesis 2.2. Male patients and female partners with more emotional problems (anxiety, depression and emotional role limitations, only male patients) were more satisfied with their relationship when they perceived more active engagement. Female patients were more satisfied with their relationship when they perceived more active engagement in all conditions of quality of life. Protective buffering had a stronger negative influence on relationship satisfaction of patients than a poorer quality of life. Partners were less satisfied with their relationship when they reported more anxiety, depression and worse social functioning.

5.4 Question 3: The role of acceptance in relationship satisfaction

In the final part of the results section, we investigated the role of acceptance in relationship satisfaction. The third research question and the two derived hypotheses were:

3. Does acceptance play a mediating role in the associations of relationship satisfaction with quality of life and support for patients and partners?

Hypothesis 3.1: The association between quality of life and relationship satisfaction is mediated by acceptance of Menière's disease for patients and partners.
Hypothesis 3.2: The association between support and relationship satisfaction is mediated by acceptance of Menière's disease for patients and partners.

5.4.1 The role of acceptance in quality of life and relationship satisfaction

Firstly, we investigated if the negative impact of a poorer quality of life on relationship satisfaction diminished or even disappeared under the influence of acceptance. In that case there was a mediating relationship. The analysis was conducted for patients and partners in two steps. In the first step, one of the six 'quality of life' variables was entered. In the second step we added acceptance. The mediating influence of acceptance was also tested with the Sobel test and the bootstrap method.

Higher acceptance of Menière's disease was able to take away the negative influence of a poorer quality of life on relationship satisfaction of patients. These results are presented in table 5.10. In other words, when patients experienced a poorer quality of life, they were more satisfied with their relationship when they accepted MD to a higher extent. The negative impact of the poorer quality of life aspects (anxiety, social functioning, vitality, physical- and emotional role limitations) disappeared when patients accepted MD. The beta weights of quality of life became smaller in step two and were not significant anymore. The influence of depression on relationship satisfaction of patients disappeared partially with higher acceptance.

Partners too, were more satisfied with their relationship when they reported more acceptance of MD. The negative impact of depression in particular, anxiety and lower vitality on their relationship satisfaction disappeared partially in case of more acceptance (showed by smaller beta weights). Acceptance showed a positive influence on relationship satisfaction of partners next to social functioning, physical- and emotional role limitations, though this was not a mediating association. Demographic variables and disease characteristics showed no influence on the role of acceptance.

Table 5.10. Regression analysis for patients and partners. Predictor variable is quality of life and mediating variable is acceptance. Dependent variable is relationship satisfaction.

	Patients			Partners		
	ß	$R^{2Change}$	Sobeltest	ß	$R^{2Change}$	Sobeltest
Anxiety 1.	*-.261***	*.068*		*-.311***	*.097*	
Anxiety 2.	-.090			-.186**		
Acceptance 2.	.330***	.080	-3.25***	.415***	.157	-3.09**
Depression 1.	*-.297***	*.088*		*-.485***	*.236*	
Depression 2.	-.162			-.375***		
Acceptance 2.	.305***	.075	-3.03**	.354***	.113	-3.07**
Social 1.	*.264***	*.070*		*.269***	*.072*	
Social 2.	.126			.223**		
Acceptance 2.	.322***	.085	3.13**	.448***	.199	1.21
Physical 1.	*.164**	*.027*		*.181**	*.033*	
Physical 2.	.035			.123*		
Acceptance 2.	.365***	.116	3.13**	.456***	.204	1.46
Emotional 1.	*.226***	*.051*		*.180**	*.033*	
Emotional 2.	.095			.185*		
Acceptance 2.	.340***	.099	3.13**	.473***	.224	-0.12
Vitality 1.	*.218***	*.048*		*.156*	*.024*	
Vitality 2.	.041			.046		
Acceptance 2.	.356***	.096	3.43***	.460***	.200	2.64**

1. Variable entered in the first step. 2. Variable entered in the second step of the analysis
Significance ß (quality of life and acceptance): *. p < .05, **. p < .01, ***. p <.001. (t (ß acceptance) = 3.53 to 6.47, p <.001). Sobeltest patients (p = .001 to .002) and Sobeltest partners (p = .002 to .910)

The results from the bootstrap method detected the same significant effects of acceptance when they were compared to the Sobel test. These confidence intervals around the mediating effect of acceptance (as computed by the bootstrap method) did not contain the value of zero. More detailed information is presented in appendix 1 table 7.

5.4.2 The role of acceptance in support and relationship satisfaction

The influence of acceptance was also investigated in the association between support and relationship satisfaction of patients and partners. We examined if the association of active engagement and protective buffering with relationship satisfaction weakened when acceptance was added. In general, acceptance predicted higher relationship satisfaction in patients and partners next to support. The results are shown in table 5.11.

Table 5.11. Regression analysis for patients and partners divided by gender. Independent variable is support (AE and PB) and mediating variable is acceptance. Dependent variable is relationship satisfaction.

	Patients			**Partners**		
	ß	$R^{2Change}$	Sobeltest	ß	$R^{2Change}$	Sobeltest
AE 1	*.643***	*.413*		*.636***	*.405*	
AE 2	.588***			.535***		
Acceptance	.246***	.058	2.24*	.203**	.031	2.57**
PB 1	*-.318***	*.101*		*-.198**	*.039*	
PB 2	-.254***			-.112		
Acceptance	.327***	.103	-2.07*	.450***	.195	-2.16*

1. Variable entered in the first step. 2. Variable entered in the second step of the analysis.
Significance ß (AE, PB and acceptance): *. p < .05, **. p < .01, ***. p <.001*. (t (ß acceptance) = 2.75 to 5.95, p = .001 to .007). Sobeltest (p = .01 to .04).

Patients and partners were more satisfied with their relationship when they perceived more active engagement and accepted MD to a higher extent. The negative impact of protective buffering on relationship satisfaction disappeared partially under influence of acceptance, particularly for partners. The influence of active engagement turned out to be stronger on relationship satisfaction than acceptance. The beta weights of AE were around 2.5 times higher than acceptance. Even though the mediating influence of acceptance was small, it showed that it is a relevant predictor in relationship satisfaction after active engagement. The bootstrap method detected the same significant effects as the Sobel test, see appendix 1 table 8. The effects of acceptance remained significant after controlling for the influence of demographic variables and disease characteristics (ß acceptance = .209 to .471).

5.4.3 Acceptance in male partners

In the descriptive analysis we found the strongest correlation coefficient for male partners of acceptance with relationship satisfaction. In contrast, acceptance showed for female partners the weakest association with relationship satisfaction. Therefore, we explored the mediating influence of acceptance more into detail for male and female partners. The results of the Sobeltest presented in table 5.12 showed that acceptance is important for male partners in particular. Acceptance significantly influenced how male partners perceived support (AE and PB) from the patient. Acceptance also partially took away the negative impact of anxiety, depression and poorer vitality on relationship satisfaction of male partners. In contrast with these findings, acceptance had no mediating influence on the associations of support and quality of life in relationship satisfaction of female partners. Beta weights of acceptance were three times stronger in male partners (ß = .449 to .657), compared to female partners (ß = -

.033 to .263). The results from the bootstrap method detected the same significant effects of acceptance when compared with the Sobeltest, see appendix 1, table 9. Demographic variables and disease characteristics showed no influence on the role of acceptance.

Table 5.12. Overview of Mediating effects of acceptance (Sobeltests) for male and female partners regarding support and quality of life. Dependent variable is relationship satisfaction.

	Acceptance Male partners Sobeltest	**Acceptance Female partners** Sobeltest
AE	3.76***	-0.32
PB	-2.36*	-0.71
Anxiety	-3.44***	-0.91
Depression	-3.28**	-0.97
Vitality	-2.42*	1.18
Social functioning	1.17	0.54
Physical role	1.56	0.54
Emotional role	0.76	-1.17

Sobeltest significant at *. p < .05, **. p < .01, ***. p <.001. P-values of the Sobeltest for male partners ranged from <.001 to .44, for female partners from .23 to .75.

We can summarize the following on the role of acceptance:

Quality of life. When patients reported a poorer quality of life and showed more acceptance of MD, they were more satisfied with their relationship. The impact of a poorer quality of life disappeared under influence of acceptance. Partners too, were more satisfied with their relationship when they accepted MD to a higher extent. The impact of depression, anxiety and poorer vitality on their relationship satisfaction partially disappeared through acceptance.

Support. Patients and partners in general were more satisfied with their relationship when they accepted MD. Acceptance partially took away the negative impact of PB on relationship satisfaction. However, patients and partners were particularly satisfied when they perceived more AE. Acceptance is a second positive factor in relationship satisfaction after perceived AE.

Acceptance of male partners. We discovered that male partners in particular were more satisfied with their relationship when they accepted MD. The impact of AE and PB on the relationship satisfaction of male partners disappeared partially under influence of acceptance. Acceptance also partially took away the negative influence of anxiety, depression and poorer vitality. The mediating influence of acceptance was not present for female partners.

General conclusion. Both partners and patients were more satisfied with their relationship when they perceived more active engagement and reported higher acceptance. Especially anxiety and depression showed a negative influence on relationship satisfaction of patients and partners. Protective buffering too had a small negative impact. However, the impact of anxiety, depression and protective buffering (partially) disappeared under the influence of acceptance and active engagement.

6. Conclusion and Discussion

Central in this study is the influence of Menière's disease on the lives of patients and partners within their relationship. More specifically, by using a research model we investigated how the relationship satisfaction of patients and partners is influenced by perceived support, quality of life and acceptance of Menière's disease. An overview of this model is presented in figure 6.1.

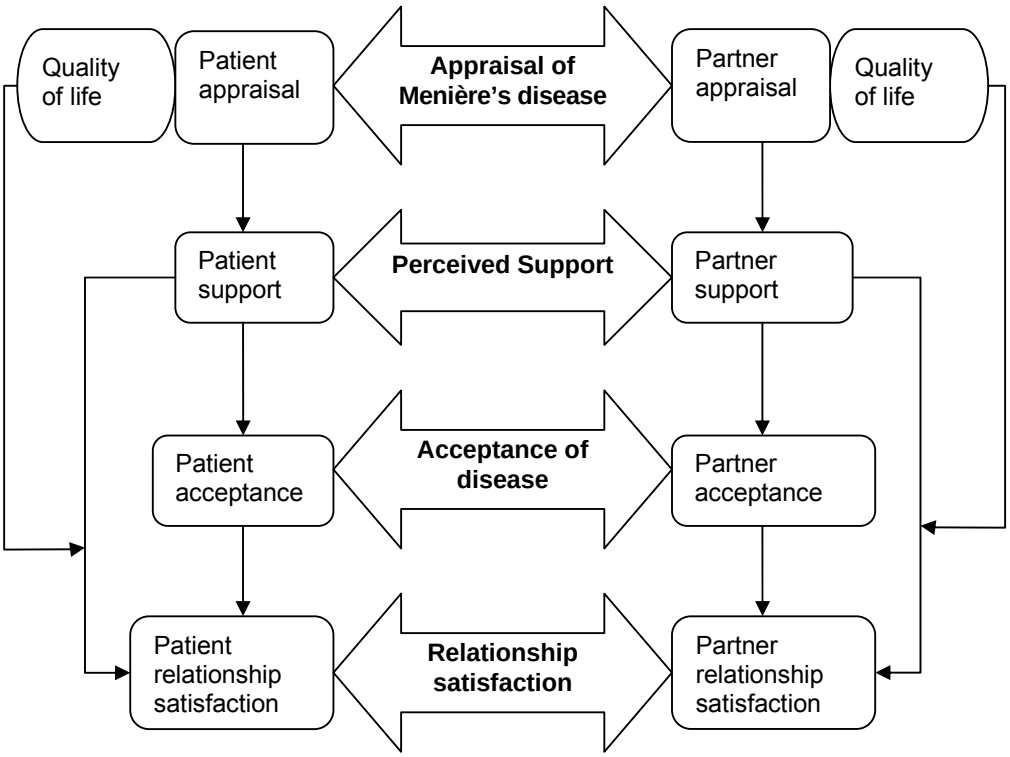


Figure 6.1. Model of support, acceptance and relationship satisfaction in Meniere's disease.

Firstly, we present the conclusions for each research question and tie these back to the research model. Secondly, we elaborate on possible explanations for our findings. In the last part we reflect on limitations of this study and offer suggestions for future research.

6.1 The role of support, quality of life and acceptance in relationship satisfaction

6.1.1 Conclusion of support and relationship satisfaction

We started to investigate the association of support with relationship satisfaction. Our expectation was that patients and partners would be more satisfied with their relationship when they perceived more active engagement. They would be less satisfied in

case of more protective buffering. For the group as a whole, active engagement had a strong and positive influence on relationship satisfaction of patients and partners. In comparison with male patients, female patients perceived significantly less active engagement and they were slightly less satisfied with their relationship. Furthermore, particularly female patients showed higher relationship satisfaction when they perceived more active engagement. Male patients reported less protective buffering than female patients. Protective buffering had a small negative influence on relationship satisfaction of patients and partners, particularly on males in the sample.

The correlation coefficients between support and relationship satisfaction and the average scores of relationship satisfaction in this study were similar to other studies of patients with cancer and couples with diabetes (Hagedoorn et al., 2000; Schokker et al., 2010). A previous study found also a stronger association of active engagement with relationship satisfaction for female cancer patients (Hagedoorn et al., 2000). Our results were in line with literature documenting that female patients are more influenced by support from their partners in comparison with male patients (Acitelli & Antonucci, 1994).

In sum, our results supported the specified associations in the model of support with relationship satisfaction for patients and partners, as presented in figure 6.1. Active engagement showed a strong and positive association and protective buffering showed a small negative association with relationship satisfaction.

6.1.2 Conclusion of quality of life, support and relationship satisfaction

The second research question examined the influence of quality of life on the association between support and relationship satisfaction of patients and partners. We hypothesized that the positive association between perceived active engagement and relationship satisfaction was stronger when patients and partners reported a poorer quality of life. This influence was particularly expected for female patients. The results showed that male patients and female partners were more satisfied with their relationship when they perceived more active engagement in case of more anxiety, depression and emotional role limitations (only male patients). This implies that the impact of active engagement on relationship satisfaction was particularly stronger with more emotional problems.

Our expectation was supported for male patients and female partners, however, not for female patients. When female patients perceived more active engagement, they reported higher relationship satisfaction in all quality of life conditions. The association of protective buffering with relationship satisfaction did not change with different levels of quality of life and disappeared in combination with active engagement. We investigated therefore the main effects. Protective buffering had a negative impact on relationship satisfaction of

patients. By contrast, partners were less satisfied with their relationship in case of more anxiety, depression and poorer social functioning, while protective buffering had no influence.

For partners, the average scores on all quality of life aspects were comparable with general populations (Van der Zee & Sanderman, 1993; Van Cruijsen et al. 2006; Spinhoven et al., 1997). Patients with Menière's disease had a poorer quality of life compared to the general population (Van der Zee & Sanderman, 1993). The quality of life aspects (social functioning, vitality, physical- and emotional role limitations) were similar to Menière patients in the study of Yardley et al. (2003). However, patients in this study reported a somewhat lower quality of life compared to patients with Menière's disease and tinnitus in other studies (e.g. Van Cruijsen et al., 2006; De Vries, 2011; Roggerone, 2010).

In sum, as specified in the model (see figure 6.1), quality of life had a moderating influence on male patients and female partners with more emotional problems, since their relationship satisfaction was higher when they perceived more active engagement.

6.1.3 Conclusion of the role of acceptance in relationship satisfaction

The third research question investigated the role of acceptance in the associations of quality of life and support with relationship satisfaction. Firstly, we expected that the association between quality of life and relationship satisfaction was mediated by acceptance for patients and partners. Secondly, we expected a mediating role of disease acceptance in the association between support and relationship satisfaction.

We start with our conclusion of the role of acceptance in relation to quality of life. Patients reported a poorer quality of life than their partners on all measured aspects. Menière's disease was also accepted to a lower extent by patients compared to partners. Female patients showed the least acceptance. When patients reported a poorer quality of life, yet they accepted Menière's disease to a higher extent, they were more satisfied with their relationship. The negative impact of a poorer quality of life disappeared through higher acceptance. Partners too, reported higher relationship satisfaction when they accepted Menière's disease to a higher extent. The negative influence of depression, anxiety and lower vitality on relationship satisfaction disappeared partially trough acceptance. In sum, our results supported the hypothesis.

We continue with our conclusion of the role of acceptance in relation to support. Acceptance had a positive influence on relationship satisfaction next to active engagement. The negative impact of protective buffering on relationship satisfaction disappeared under influence of acceptance for partners and it partially disappeared for patients. Patients and partners however, were particularly satisfied with their relationship when they perceived more active engagement. This implies that after active engagement, disease acceptance is but a

second positive factor in predicting relationship satisfaction.

Acceptance proved to be more important for male partners than for female partners. Unexpectedly, we discovered that especially male partners were more satisfied with their relationship when they reported higher acceptance. The impact of active engagement and protective buffering on relationship satisfaction of male partners disappeared partially under influence of acceptance. The negative influence of anxiety, depression and lower vitality disappeared also partially through acceptance. Acceptance had no impact on female partners.

The average acceptance of patients in this study was comparable with another study of Menière patients (De Vries, 2011). De Vries (2011) showed that acceptance played an important role in predicting quality of life Acceptance in this study was also comparable with a study of patients with rheumatoid arthritis and multiple sclerosis which showed also strong associations with their quality of life (Evers et al., 1998). The positive influence of acceptance in our study is in line with the literature documenting the positive outcomes of acceptance in other chronic conditions which are difficult to control, like tinnitus and chronic pain (Schutte et al., 2009; McCracken & Eccleston, 2003). Partners are also affected by Menière's disease and can experience more emotional problems (Kuyper, 1993). Our results are in line with the literature reviewed in the introduction that partners benefit as well from the acceptance of disease. Tension and emotional problems in their relationship decreased when partners reported higher acceptance (Kuyper, 1993; Scarinci et al., 2008).

In sum, our results supported the specified mediating role of acceptance in the association of quality of life with relationship satisfaction of patients and partially for partners. The results provided also partial support for the mediating role of acceptance in the association of support with relationship satisfaction, as was specified in the model (figure 6.1). For male partners in particular, acceptance was a mediating factor in the association of active engagement and protective buffering with relationship satisfaction. For patients, acceptance mediated the association of protective buffering with relationship satisfaction. Active engagement proved to be a stronger predictor than acceptance in relationship satisfaction.

6.2 Degree of interdependence in relationships

6.2.1 Interdependence in relationships

We showed in the introduction that patients and partners are interdependent in their relationship and in their coping with Menière's disease, while each partner can influence the other partner during their interactions (Bodenmann, 2005; Rusbult & Buunk, 1993; Berg & Upchurch 2007). In line with the literature on active engagement (Schokker et al., 2010; Badr, 2004) patients and partners all were more satisfied with their relationship when they

perceived more active engagement from each other, irrespective of their role and gender. This means that when they perceived that the other partner was actively talking with them about problems and sharing thoughts and feelings they evaluated their relationship in a more positive way. Active engagement fosters intimacy in couples and increases commitment and interdependence (Rusbult & Buunk, 1993). Partners share each others experiences on 'bad' days as well and have the most knowledge of each others situation, compared to others in the social network. Support of partners is therefore also the most important source of support (Revenson, 1994). In case of high anxiety and depression we found that male patients and their female partners reported higher relationship satisfaction when they perceived more active engagement. Stronger commitment to a relationship fosters positive behaviours, such as active engagement, to maintain relationship satisfaction in dealing with a chronic illness (Rusbult & Buunk, 1993; Bodenmann, 2005).

The negative influence of protective buffering on relationship satisfaction was marginally significant. We did not find a moderating effect in relation to protective buffering either. The literature reviewed in the introduction showed that protective buffering could be particularly stronger under certain conditions, such as less perceived active engagement or a poorer quality of life (Schokker et al., 2010; Hagedoorn et al., 2000). The impact depends on the interpretation of protective buffering, while patients and partners can make different attributions for this support (Bradbury & Fincham, 1990; Schokker et al., 2010). They can perceive it as regular and intentional or just now and then. Couples with high commitment are more likely to use accommodating behaviour in conflicts to maintain relationship satisfaction (Rusbult & Buunk, 1993). It is possible that satisfied couples make more benign attributions and forgive protective buffering more easily (Schokker, 2010).

6.2.2 Differences in degree of interdependence among males and females

In the reviewed literature we described that individuals are interdependent in their relationship. Beside, individuals are also different in the way they view themselves in a relationship (Rusbult & Buunk, 1993; Cross & Madson, 1997). Men tend to view themselves as more independent in relationships (independent self-construal) and they make a sharper distinction between themselves and others (Cross & Madson, 1997). Women, on the contrary, see themselves more as interdependent in relationships and connected with others (interdependent self-construal). As a consequence, men and women differ in their use of coping strategies. Men tend to use more problem-focused coping strategies (to plan out ways to solve or remove a problem), while women are more likely to regulate emotions and seeking social support (Ptacek, Ptacek & Dodge, 1994; Lazarus & Folkman, 1984). In this study relationship satisfaction of female patients in particular increased with more

perceived active engagement, which was in line with the reviewed literature (Hagedoorn et al., 2000) and the notion that females benefit from social support due to interdependent self-construal (Cross & Madson, 1997).

Another finding in our study was that male patients and their female partners with more emotional problems reported higher relationship satisfaction when they perceived more active engagement. This was in line with the reviewed literature of tinnitus patients and other chronic illnesses. Patients with tinnitus reported less disability when they received more social support and positive interaction was particularly important for patients with high depression (Sullivan et al., 1994). In other studies too, we see that due to a chronic illness, patients and partners experience emotional problems (Yardley et al., 2003; Wright & Acquilino, 1998; Kuyper, 1993). The question is however, how they cope with the emotional problems.

Badr (2004) investigated support in couples dealing with several chronic diseases (i.e. cancer, diabetes, auto-immune and heart diseases). In this study male patients, compared to female patients and healthy males, used more active engagement as a way of problem-focused coping. Male patients showed the same level of active engagement as their female partners (Badr, 2004). Usually males tend to spend less attention to their emotions compared to females (Cross & Madson, 1997). Possibly male patients in this study with high emotional problems needed active engagement in particular under these circumstances as a way of problem focused coping. This is in line with Accitelli (2002) who suggested that males find communication important in dealing with problems. Communication for males is less important for their relationship satisfaction overall.

Females in general are more affected by emotional experiences and events in their family compared to males (Cross & Madson, 1997; Conger, Lorenz, Elder Jr., Simmons & Ge, 1993). In line with this finding in the literature is a meta-analysis of forty-six studies of couples dealing with cancer (Hagedoorn, Sanderman, Bolks, Tuinstra & Coyne, 2008). Hagedoorn et al. (2008) showed in this meta-analysis that females experienced more distress than men irrespective of being a patient or a partner. Thus, when male patients experience more emotional problems, female partners too, could be affected by this distress (Bodenmann, 2005). For females communication in their relationship was related to their wellbeing (Acitelli, 2002). This implicates that through more active engagement, female partners are able to deal with emotional problems.

Several studies (Badr, 2004; Hickson et al., 2008) indicate that male patients show better adjustment to a disease compared to female patients. In the current study female patients reported lower relationship satisfaction, poorer acceptance and perceived less active engagement compared to male patients. In line with this study, Badr (2004) found that couples with a female patient used less active engagement than male patients. Another

study indicated females with hearing impairment perceived less understanding and were less encouraged to use hearing aids compared to males (Jones, Kyle & Wood, 1987). Other studies found that female patients with hearing impairment reported lower well-being, more awareness of communication problems and they perceived social communication as more important than males (Hickson et al., 2008; Garstecki & Erler, 1999; Demorest & Erdman, 1987). In this study we found gender differences among male and female patients in coping, however not in quality of life aspects. Hagedoorn et al. (2000) found a moderating effect of quality of life for female cancer patients. In this study we also expected a moderating effect of quality of life for female patients; however this was not the case. Female patients benefited from active engagement in all quality of life conditions. Acitelli (2002) showed that for females communication about the relationship was associated with their relationship satisfaction. Particularly females with Menière's disease may view that active engagement is important in dealing with problems and in normal situations. In sum, for male patients active engagement is particularly important for their relationship satisfaction in dealing with emotional problems. For female partners with emotional problems active engagement is of particular importance too in this situation. Female patients perceive less active engagement and this way of support is more important overall for their relationship satisfaction.

6.2.3 Acceptance for partners

Acceptance is an individual and intrapersonal strategy to deal with a disease (McCracken & Eccleston, 2003) while active engagement is an interpersonal support strategy in the interaction between partners (Bodenmann, 2005). Active engagement showed a stronger influence on relationship satisfaction than acceptance. The results are in line with a reviewed study. Papp & Witt (2010), found that support strategies contributed stronger to relationship satisfaction compared to individual coping strategies.

Still, an intrapersonal strategy like acceptance is a significant positive predictor in relationship satisfaction of patients and male partners. Within couples individuals can differ in their preference for the use of active engagement and acceptance. For example we found that acceptance had a mediating role for male partners, but not for female partners.

Male partners benefit from both acceptance and active engagement. More specifically, acceptance partially removes the negative influence of protective buffering and a poorer quality of life. Moreover, active engagement influences their relationship satisfaction through acceptance. Male partners view themselves as independent within a relationship. They are less likely to spend attention to their emotions and to use social support as a coping strategy, since they share not so easily their thoughts and feelings with

others (Cross & Madson, 1997). An intrapersonal strategy like acceptance therefore seems to be an adequate strategy for male partners. Acceptance had no influence on female partners. An explanation is that female partners view themselves as more interdependent in relationships and that active engagement allows them to deal with their own thoughts and feelings (Cross & Madson, 1997; Badr, 2004). This explanation is also supported by our finding that female partners with high emotional problems reported higher relationship satisfaction when they perceived more active engagement.

6.3 Considerations for the current study and future research

6.3.1 Limitations of this study

The current study showed clear and relevant results which contribute to further theoretical development and has practical implications. At the same time there were some limitations of this study. The first limitation is that through the use of a cross-sectional design we were not able to draw causal conclusions from the analysis.

A second limitation was that participants were members of a patient organization, who could be more active and involved than average. It is also possible that patients who are members of an organization experience a poorer quality of life than average patients. The patients in our sample experienced a slightly poorer quality of life than other studies with Menière patients (Van Cruijsen et al., 2006; De Vries, 2011) and they could have been more motivated to participate in the research. There is no gender difference in the prevalence of Menière's disease (Van Cruijsen, 2006). However, we had somewhat more female patients in our sample than male patients. While females spend more attention to their relationship (Cross & Madson, 1997) they could have been more motivated to participate in the study. Therefore it is possible that the sample is not entirely representative for the population of patients with Menière's disease and their partners.

The reliability of the scale which measured protective buffering was acceptable, however relatively low compared to the other subscales (Cronbach's alpha PB = .635 to .693 and AE = .822 to .886). The lower reliability of protective buffering is consistent with other studies (Hagedoorn et al., 2000; Schokker et al., 2010). The impact of protective buffering could depend on the attributions made by individuals (Schokker et al., 2010).

6.3.2 Suggestions for future research

Future research could take gender differences into account, while we found different patterns for male and female patients and partners and they showed different needs in dealing with Menière's disease. Further, the average duration of Menière's disease

was more than a decade. It is likely that couples during this time adjusted to Menière's disease. Future studies could include patients and their partners who have been diagnosed with Menière's disease only recently and follow these couples over time. Following this way, useful insight can be obtained in the development of support and acceptance in the adjustment to Menière's disease over time. This study and future research can be used to develop tailor-made interventions for patients and partners to improve and sustain their relationship satisfaction and quality of life.

The different components in this study showed obvious associations with relationship satisfaction. These associations were similar to other studies which used general methods or more sophisticated statistical methods (Badr, 2004; Hagedoorn et al., 2000; Schokker et al., 2010). A next step in the analyses could be the use of more sophisticated statistical techniques (like multilevel analysis) to estimate the degree of interdependence between patients and partners, as these techniques are able to analyze data on a dyadic level. Badr (2004) found that the similarity in active engagement and complementation in protective buffering played a role in relationship satisfaction. This was irrespective of high or low levels of support. This finding is worth further investigation and could be assessed with multilevel analysis as well.

6.4 General Conclusion

The general influence of Menière's disease on the lives of patients and partners within their relationship could be noticed through several components. As a consequence of Menière's disease, particularly anxiety and depression had a negative influence on relationship satisfaction of patients and partners. More important though, are the factors of active engagement and acceptance which enable patients and partners to deal with the consequences of Menière's disease. Within their relationship patients and partners frequently interact with each other. Patients and partners are interdependent and they are more satisfied with their relationship if they perceive more active engagement from each other. In addition to this, females view themselves as more interdependent and connected in relationships compared to males. Females in general and especially female patients benefit from active engagement, which is the strongest sustaining factor in their relationship satisfaction.

Acceptance of Menière's disease is a second factor in promoting relationship satisfaction of patients and partners. Acceptance decreased the perceived negative consequences of Menière's disease such as a poorer quality of life. For patients the negative influence of emotional problems on their relationship satisfaction disappeared through acceptance. Acceptance was important for relationship satisfaction of male

partners too, while acceptance influenced their perception of support and quality of life. It is possible that higher acceptance in male partners contributes to better adjustment to Menière's disease of couples with a female patient overall. In contrast, acceptance was not important for female partners. The results emphasized the importance of studying the specific coping styles related to gender and the role of patient or partner and to acknowledge that individuals within couples can differ in what they need to deal with Menière's disease.

Anxiety, depression and protective buffering have a negative influence on relationship satisfaction of patients and partners. However, this negative influence can be (partially) overcome by active engagement and acceptance of Menière's disease. The associations of support with relationship satisfaction were previously investigated in couples dealing with cancer and diabetes. The associations of support and acceptance with relationship satisfaction have now been studied in couples dealing with an inner ear disorder. The findings of this study are important for couples dealing with Menière's disease, other inner ear disorders and chronic illness in general. For couples who experience problems in dealing with Menière's disease relationship counseling can improve their circumstances. A study in which couples received counseling while they were dealing with cancer showed promising results. After the received counseling, patients and partners reported an increase in active engagement and a better quality of the relationship (Kuijer, Buunk, De Jong, Ybema & Sanderman, 2004). Kuijer et al. (2004) found that couples reported also more equality within their relationship and a decreased level of depression.

7. References

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Appendix

Appendix 1: Tables and Figures

Figure 1. Overview of patients and partners with co-morbidities in percentages.

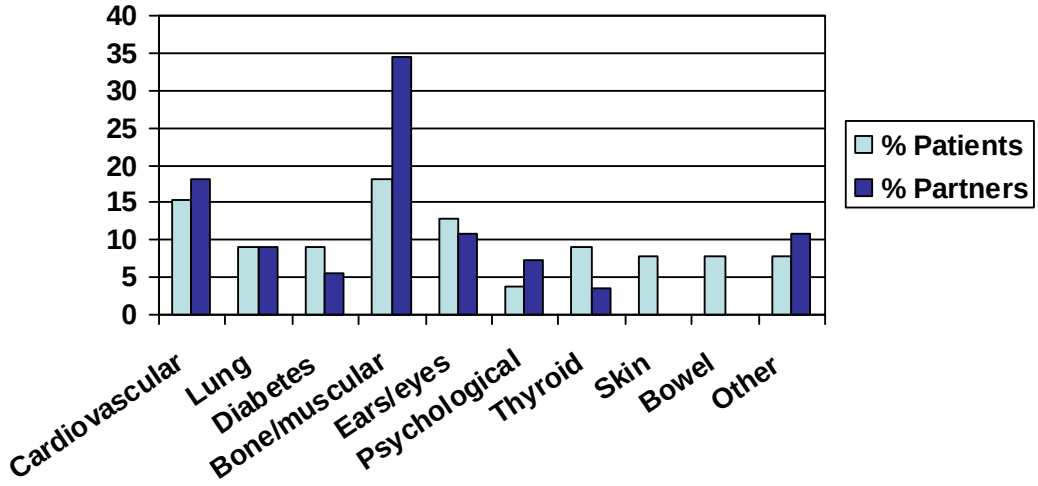

Table 1. Correlation coefficients for patients of demographic variables and disease characteristics with the dependent and independent variables.

	Edu-cation level	Age	Duration relation-ship	Work force status	Length of MD	Severity Hearing loss	Severity tinnitus	Severity of Vertigo
Relationship satisfaction	-.004	.121	.139	.098	-.073	-.090	-.116	-.209*
Acceptance	.075	.346**	.229**	.056	.171*	.045	-.269**	-.241*
Received AE	-.050	.103	.086	.125	.041	-.047	-.031	-.005
Received PB	-.205*	-.003	.071	.077	-.001	.097	.082	.081
Anxiety	-.221**	-.090	-.108	.115	.085	.061	.127	.263**
Depression	-.257**	-.074	-.041	.067	.089	.233**	.254**	.315**
Social functioning	.058	.096	.140	-.048	-.095	-.238**	-.376**	-.434**
Physical role	.017	.296**	.279**	.078	.048	-.068	-.207*	-.469**
Emotional role	.214*	.086	.086	.005	-.095	-.139	-.270**	-.413**
Vitality	.176*	.229**	.230**	-.043	-.144	-.094	-.355**	-.423

*. Correlation is significant at the 0.05 level (two-tailed).
**. Correlation is significant at the 0.01 level (two-tailed).

Table 2. Correlation coefficients for partners of demographic variables with the dependent and independent variables.

	Education level	Work-status	Age	Duration relation-ship
Relationship satisfaction	-.188*	.099	.144	.109
Acceptance	-.198*	.102	.245**	.080
Received AE	-.163	.167*	.180*	.141
Received PB	.033	.177*	.108	.203*
Anxiety	.018	.103	-.055	-.037
Depression	-.034	.023	-.026	.001
Social functioning	.028	-.064	-.058	-.037
Physical role	.019	-.127	-.004	.031
Emotional role	-.058	-.022	-.019	.033
Vitality	.039	-.053	.082	.057

*. Correlation is significant at the 0.05 level (two-tailed).
**. Correlation is significant at the 0.01 level (two-tailed).

Table 3: Significant chi-square tests for patients and partners of gender, tinnitus and co-morbidities with the independent variables.

	Variables	Chi-square	Sig
Patients	Gender and depression	24.75	.053
	Gender and PB	34.44	.032
	Tinnitus (in one, both or no earse) and PB	69.84	.004
Partners	Co-morbidities and Social functioning	22.25	.004
	Co-morbidities and physical role lim.	38.22	.001
	Co-morbidities and emotional role lim.	11.04	.011

Table 4. Number of male patients and female partners per low and high level of quality of life and low, middle and high level of active engagement.

	AE male patients (N = 64)			AE female partners (N = 64)		
	Low	Middle	High	Low	Middle	High
Anxiety low	4	17	10	9	15	9
Anxiety high	7	14	12	9	10	12
Depression low	7	15	12	9	14	9
Depression high	4	16	10	9	11	12
Emotional role low	7	12	10	2	2	5
Emotional role high	4	19	12	16	23	16
Social functioning low				8	10	11
Social functioning high				10	15	10

Table 5. Regression analysis for female patients. Predictor variables are AE and quality of life. Dependent variable is relationship satisfaction.

	Female Patients	
	ß	R^2
AE	.669***	.477
Anxiety	-.122	
AE	.655***	.505
Depression	-.208*	
AE	.645***	.498
Social Funct.	.192*	
AE	.671***	.467
Physical role	.069	
AE	.681***	.479
Emotional role	.130	
AE	.662***	.520
Vitality	.241**	

Female patients: N = 78. Significance of the beta weights: *. p < .05, **. p < .01, ***. p <.001.
(t (AE) = 7.75 to 8.25, p < .001. (t (Quality of life) = -2.55 to 3.00, p = .004 to .420.

Table 6. Regression analysis for patients and partners. Predictor variables are protective buffering and quality of life. Dependent variable is relationship satisfaction.

	Patients beta	R^2	**Partners** beta	R^2
PB Anxiety	-.262** -.178*	.129***	-.101 -.275**	.106***
PB Depression	-.280*** -.256***	.165***	-.090 -.464***	.242***
PB Social Funct.	-.283*** .219**	.148***	-.155 .241**	.096***
PB Physical role	-.307*** .139	.120***	-.161 .136	.056
PB Emotional role	-.286*** .172*	.130***	-.165 .141	.058
PB Vitality	-.301*** .192*	.138***	-.168 .110	.050

Significance of the beta weights: *. p < .05, **. p < .01, ***. p <.001. PB patients (t = -.385 to -3.13, p <.001 to .002.). Quality of life patients (t = -3.27 to 2.76, p = .001 to .083.
PB partners (t = -1.95 to -1.89, p = .053 till .061).
Quality of life partners (t = -6.12 to 2.94, p = .001 to .115).

Table 7. Bootstrap analysis for patients and partners. Independent variable is quality of life and mediating variable is acceptance. Dependent variable is relationship satisfaction.

	Patients Acceptance				**Partners Acceptance**			
	Effect Sample	Effect Bootstrap	95%CI bootstrap Bias corrected Lower	Upper	Effect Sample	Effect Bootstrap	95%CI bootstrap Bias corrected Lower	Upper
Anxiety	-.0397*	-.0394**	-.0692	-.0197	-.0328*	-.0335**	-.0644	-.0109
Depression	-.0338*	-.0339**	-.0636	-.0149	-.0342*	-.0355**	-.0644	-.0104
Social	.0055*	.0055**	.0023	.0100	.0021	.0023	-.0014	.0070
Physical	.0033*	.0032**	.0017	.0057	.0016	.0016	-.0006	.0041
Emotional	.0031*	.0031**	.0014	.0057	-.0002	.0014	-.0034	.0034
Vitality	.0085*	.0085**	.0040	.0151	.0062*	.0062**	.0020	.0116

* Effect sample significant according to the Sobel test.
** Effect bootstrap significant according to Bootstrap method.

Table 8. Bootstrap analysis for patients and partners. Independent variables are AE and PB and mediating variable is acceptance. Dependent variable is relationship satisfaction.

	Patients Acceptance				Partners Acceptance			
	Effect Sample	Effect Bootstrap	95%CI bootstrap Bias corrected Lower	Upper	Effect Sample	Effect Bootstrap	95%CI bootstrap Bias corrected Lower	Upper
AE	.0142*	.0144**	.0042	.0330	.0311*	.0333**	.0015	.0679
PB	-.0152*	-.0155**	-.0359	-.0034	-.0211*	-.0214**	-.0451	-.0024

* Effect sample significant according to the Sobel test.
** Effect bootstrap significant according to Bootstrap method.

Table 9. Bootstrap analysis for male and female partners. Independent variables are support or quality of life and mediating variable is acceptance. Dependent variable is relationship satisfaction.

	Male partners Acceptance				Female Partners Acceptance			
	Effect Sample	Effect Bootstrap	95%CI bootstrap Bias corrected Lower	Upper	Effect Sample	Effect Bootstrap	95%CI bootstrap Bias corrected Lower	Upper
AE	.0849*	.0856**	.0486	.1337	-.0037	.0001	-.0368	.0260
PB	-.0403*	-.0406**	-.0796	-.0084	-.0056	-.0061	-.0367	.0092
Anxiety	-.0630*	-.0646**	-.1104	-.0216	-.0077	-.0092	-.0437	.0042
Depression	-.0655*	-.0666**	-.1130	-.0271	-.0087	-.0129	-.0451	.0045
Vitality	.0468*	.0466**	.0111	.0885	.0027	.0029	-.0006	.0106
Social	.0040	.0044	-.0035	.0125	.0006	.0010	-.0012	.0060
Physical	.0033	.0032	-.0011	.0076	.0004	.0004	-.0009	.0031
Emotional	.0018	.0019	-.0037	.0076	-.0019	-.0016	-.0055	.0011

* Effect sample significant according to the Sobel test.
** Effect bootstrap significant according to Bootstrap method.

Appendix 2: Information letters

Brief bij vragenlijst via internet

Kenmerk:
Betreft: Ménière–enquête patiënten en partners
Respondentnummer: **XXXX**

Houten, ...februari 2011

Geachte heer, mevrouw,

Het moment is aangebroken dat we u de vragenlijsten kunnen voorleggen betreffende het onderzoek naar de invloed van de ziekte van Ménière op het leven van patiënten en hun partners.

Zoals u beiden wellicht kunt beamen kan de ziekte van Ménière invloed hebben op het leven van patiënten en hun partners en op de relatie die zij hebben. Daarom heeft de Wetenschapswinkel Geneeskunde en Volksgezondheid van de Rijksuniversiteit te Groningen, in samenwerking met onze commissie, besloten hier onderzoek naar te doen. Wij hopen dat u, als patiënt en als partner van de patiënt, allebei aan dit onderzoek wilt meewerken. Voor dit onderzoek is het namelijk van groot belang om onderlinge verschillen en overeenkomsten te kunnen vergelijken in de manier waarop de ziekte van Ménière van invloed is op het leven van patiënten èn hun partners.

Het onderzoek bestaat uit een vragenlijst die u allebei onafhankelijk van elkaar invult, met gedeeltelijk dezelfde en gedeeltelijk verschillende vragen. Het invullen van de vragenlijst kost ongeveer een half uur. Deze brief, gericht aan beide partners, is verstuurd naar de e-mailadressen van de Ménière patiënten die zich hebben aangemeld. Indien u geen gezamenlijk e-mailadres heeft, wilt u dan deze brief doorsturen naar het e-mailadres van uw partner?

Als u besluit om met uw partner mee te doen aan het onderzoek, dan verzoeken wij u op deze link te klikken: **Naar de vragenlijst**
Deze link brengt u rechtstreeks naar de vragenlijst. U kunt via deze link de vragenlijsten allebei **onafhankelijk** van elkaar invullen**.

Wanneer u start met de vragenlijst verzoeken wij u het volgende respondentnummer **XXXX** in te vullen. Dit nummer is hetzelfde voor beide partners en is noodzakelijk om gegevens van patiënten en hun partners bij de analyse aan elkaar te kunnen koppelen en te vergelijken. Dit nummer wordt uitsluitend hiervoor gebruikt. Uw gegevens zullen vertrouwelijk worden behandeld en volledig anoniem worden verwerkt. Tevens zullen bij presentatie van resultaten gegevens van individuele personen onherkenbaar zijn.

Het is de bedoeling dat u de vragenlijst in één keer invult. Daarnaast is het voor een zo goed mogelijk onderzoeksresultaat van belang dat u alle vragen invult en dat u beiden niet met elkaar spreekt over de vragenlijst totdat u de vragen allebei apart van elkaar heeft ingevuld.
Graag zien we uw vragenlijst binnen een week tegemoet.

Indien u vragen heeft over de enquête, dan kunt u contact opnemen met

Dr. J. Tuinstra
Coördinator Wetenschapswinkel
Geneeskunde en Volksgezondheid
Tel.: 050-3639080
E-mail: j.tuinstra@med.umcg.nl

M. Kaper-Hulzebos
Student onderzoeker
Master Psychologie
E-mail: m.kaper@student.rug.nl

Ook namens hen danken we u alvast hartelijk voor uw medewerking. Wij zullen u over de resultaten van het onderzoek berichten in het tijdschrift HOREN van de NVVS.

Met vriendelijke groet,
NVVS
Sandra Rutgers, arts MPH
Voorzitter NVVS-Commissie Ménière

** Indien de directe link naar de vragenlijst niet werkt, druk dan de controltoets in op uw toetsenbord en klik met de muis op de directe link, of kopieer de volgende link en plak deze in de adresbalk van uw browser: http://survey.qualtrics.com/SE/?SID=SV_5zNR7MdvTVKW4Dy

Brief bij vragenlijst per post

Kenmerk:
Betreft: Ménière –enquête patiënten en partners
Respondentnummer: **XXXX**

Houten, ...februari 2011

Geachte heer, mevrouw,

Het moment is aangebroken dat we u de vragenlijsten kunnen voorleggen betreffende het onderzoek naar de invloed van de ziekte van Ménière op het leven van patiënten en hun partners.

Zoals u beiden wellicht kunt beamen kan de ziekte van Ménière invloed hebben op het leven van patiënten en hun partners en op de relatie die zij hebben. Daarom heeft de Wetenschapswinkel Geneeskunde en Volksgezondheid van de Rijksuniversiteit te Groningen, in samenwerking met onze commissie, besloten hier onderzoek naar te doen. Wij hopen dat u, als patiënt en als partner van de patiënt, allebei aan dit onderzoek wilt meewerken. Voor dit onderzoek is het namelijk van groot belang om onderlinge verschillen en overeenkomsten te kunnen vergelijken in de manier waarop de ziekte van Ménière van invloed is op het leven van patiënten èn hun partners. Het onderzoek bestaat uit een vragenlijst die u allebei onafhankelijk van elkaar invult, met gedeeltelijk dezelfde en gedeeltelijk verschillende vragen. Het invullen van de vragenlijst kost ongeveer een half uur.

Als u samen met uw partner besluit om mee te doen aan het onderzoek, dan verzoeken wij u beiden de twee bijgevoegde exemplaren van de vragenlijst (een exemplaar voor de Ménière patiënt en een exemplaar voor diens partner) onafhankelijk van elkaar in te vullen en de vragenlijsten apart van elkaar te retourneren in een van de bijgevoegde geadresseerde enveloppen. U hoeft geen postzegel te plakken!

Wanneer u start met de vragenlijst verzoeken wij u het volgende respondentnummer **XXXX** in te vullen. Dit nummer is hetzelfde voor beide partners en is noodzakelijk om gegevens van patiënten en hun partners bij de analyse aan elkaar te kunnen koppelen en te vergelijken. Dit nummer wordt uitsluitend hiervoor gebruikt. Uw gegevens zullen vertrouwelijk worden behandeld en volledig anoniem worden verwerkt. Tevens zullen bij presentatie van resultaten gegevens van individuele personen onherkenbaar zijn.

Het is de bedoeling dat u de vragenlijst in één keer invult. Daarnaast is het voor een zo goed mogelijk onderzoeksresultaat van belang dat u alle vragen invult en dat u beiden niet met elkaar spreekt over de vragenlijst totdat u de vragen allebei apart van elkaar heeft ingevuld.
Graag zien we uw vragenlijst binnen een week tegemoet.

Indien u vragen heeft over de enquête, dan kunt u contact opnemen met

Dr. J.Tuinstra
Coördinator Wetenschapswinkel
Geneeskunde en Volksgezondheid
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Marise Kaper-Hulzebos
Student onderzoeker
Master Psychologie
E-mail: m.kaper@student.rug.nl

Ook namens hen danken we u alvast hartelijk voor uw medewerking. Wij zullen u over de voortgang van het onderzoek via het tijdschrift HOREN van de NVVS op de hoogte houden.

Met vriendelijke groet,
NVVS
Sandra Rutgers, arts MPH
Voorzitter NVVS-Commissie Ménière

Appendix 3: Reminding letters

Brief via internet

Kenmerk:
Betreft: Ménière–enquête patiënten en partners
Respondentnummer: **XXXX**

Houten, ... maart 2011

Geachte heer, mevrouw,

Op dit moment is het twee weken geleden dat we u de vragenlijsten hebben voorgelegd over het onderzoek naar de invloed van de ziekte van Ménière op het leven van patiënten en hun partners. Dit onderzoek wordt verricht door de Wetenschapswinkel Geneeskunde en Volksgezondheid van de Rijksuniversiteit te Groningen in samenwerking met onze commissie.
In de tussenliggende tijd hebben wij al een aantal reacties mogen ontvangen. Vanwege de anonimiteit van de respondenten weten wij echter niet of u al heeft deelgenomen aan het onderzoek.

Indien u zowel als uw partner de vragenlijsten al hebben ingevuld, willen wij u hartelijk bedanken voor uw deelname aan het onderzoek!

Van de personen die tot nu toe de vragenlijst hebben ingevuld heeft 61% de ziekte van Ménière en is 39% partner van een Ménière patiënt. Voor dit onderzoek is het juist van groot belang dat ook de partners van Ménière patiënten de vragenlijst invullen. Op die manier kunnen we een vergelijking maken wat de invloed is van de ziekte van Ménière op het leven van zowel patiënten èn hun partners en op hun relatie.

Indien u nog niet heeft deelgenomen aan het onderzoek verzoeken wij u daarom vriendelijk om de vragenlijsten alsnog in te vullen.

Deze brief, gericht aan beide partners, is verstuurd naar de e-mailadressen van de Ménière patiënten. Wilt u wanneer dit van toepassing is, deze brief doorsturen naar het e-mailadres van uw partner?

Wanneer u alsnog besluit om met uw partner mee te doen aan het onderzoek, dan verzoeken wij u op deze link te klikken: **Naar de vragenlijst**
Deze link brengt u rechtstreeks naar de vragenlijst. U kunt via deze link de vragenlijsten allebei **onafhankelijk** van elkaar invullen**.

Ter herinnering hebben wij nog een keer het respondentnummer **XXXX** vermeld dat u nodig heeft wanneer u start met de vragenlijst. Dit nummer is hetzelfde voor beide partners en wordt uitsluitend gebruikt om gegevens van patiënten en hun partners te kunnen vergelijken.
Uw gegevens zullen vertrouwelijk worden behandeld en volledig anoniem worden verwerkt.

Graag zien we uw vragenlijst alsnog binnen een week tegemoet.

Helaas is na het verzenden van de vorige brief gebleken dat het e-mailadres van de student onderzoeker onjuist was weergegeven. Dit e-mailadres is nu wel correct vermeld.
Indien u vragen heeft over de vragenlijst of het onderzoek, dan kunt u contact opnemen met

Dr. J. Tuinstra
Coördinator Wetenschapswinkel
Geneeskunde en Volksgezondheid
Tel.: 050-3639080
E-mail: j.tuinstra@med.umcg.nl

M. Kaper-Hulzebos
Student onderzoeker
Master Psychologie
E-mail: m.s.kaper@student.rug.nl

Ook namens hen danken we u alsnog hartelijk voor uw medewerking. Wij zullen u over de resultaten van het onderzoek berichten in het tijdschrift HOREN van de NVVS en een samenvatting van het onderzoek zal u per e-mail worden toegezonden.

** Indien de directe link naar de vragenlijst niet werkt, druk dan de controltoets in op uw toetsenbord en klik met de muis op de directe link, of kopieer de volgende link en plak deze in de adresbalk van uw browser: http://survey.qualtrics.com/SE/?SID=SV_5zNR7MdvTVKW4Dy

Met vriendelijke groet,
NVVS
Sandra Rutgers, arts MPH
Voorzitter NVVS-Commissie Ménière

Brief via post

Kenmerk:
Betreft: Ménière–enquête patiënten en partners
Respondentnummer: **XXXX**

Houten, ... maart 2011

Geachte heer, mevrouw,

Op dit moment is het twee weken geleden dat we u de vragenlijsten hebben voorgelegd over het onderzoek naar de invloed van de ziekte van Ménière op het leven van patiënten en hun partners. Dit onderzoek wordt verricht door de Wetenschapswinkel Geneeskunde en Volksgezondheid van de Rijksuniversiteit te Groningen in samenwerking met onze commissie.
In de tussenliggende tijd hebben wij al een aantal reacties mogen ontvangen. Vanwege de anonimiteit van de respondenten weten wij echter niet of u al heeft deelgenomen aan het onderzoek.

Indien u zowel als uw partner de vragenlijsten al hebben ingevuld, willen wij u hartelijk bedanken voor uw deelname aan het onderzoek!

Van de personen die tot nu toe de vragenlijst hebben ingevuld heeft 61% de ziekte van Ménière en is 39% partner van een Ménière patiënt. Voor dit onderzoek is het juist van groot belang dat ook de partners van Ménière patiënten de vragenlijst invullen. Op die manier kunnen we een vergelijking maken wat de invloed is van de ziekte van Ménière op het leven van zowel patiënten èn hun partners en op hun relatie.

Indien u nog niet heeft deelgenomen aan het onderzoek verzoeken wij u daarom vriendelijk om de vragenlijsten alsnog in te vullen en retour te zenden.

Ter herinnering hebben wij nog een keer het respondentnummer **XXXX** vermeld dat u nodig heeft wanneer u start met de vragenlijst. Dit nummer is hetzelfde voor beide partners en wordt uitsluitend gebruikt om gegevens van patiënten en hun partners te kunnen vergelijken.
Uw gegevens zullen vertrouwelijk worden behandeld en volledig anoniem worden verwerkt.
Wanneer de vragenlijst(en) onverhoopt zijn zoekgeraakt, zou u dan contact met ons op willen nemen? We zullen u dan zo spoedig mogelijk nieuwe lijsten toezenden.

Graag zien we uw vragenlijst alsnog binnen een week tegemoet.

Helaas is na het verzenden van de vorige brief gebleken dat het e-mailadres van de student onderzoeker onjuist was weergegeven. Dit e-mailadres is nu wel correct vermeld.

Indien u vragen heeft over de vragenlijst of het onderzoek, dan kunt u contact opnemen met

Dr. J. Tuinstra
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M. Kaper-Hulzebos
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Ook namens hen danken we u alsnog hartelijk voor uw medewerking. Wij zullen u over de resultaten van het onderzoek berichten in het tijdschrift HOREN van de NVVS en een samenvatting van het onderzoek zal u per post worden toegezonden.

Met vriendelijke groet,
NVVS
Sandra Rutgers, arts MPH
Voorzitter NVVS-Commissie Ménière

Appendix 4: Questionnaire patients and partners

The overlapping parts in the questionnaire of patients and partners have been removed from the questionnaire for partners.

Instructie Vragenlijst

U doet mee aan dit onderzoek vanwege het feit dat u de ziekte van Ménière heeft of omdat u partner bent van een Ménière patiënt. Door middel van deze vragenlijst hopen wij een zo compleet mogelijk beeld te krijgen van de invloed van de ziekte van Ménière op het leven van Ménière patiënten en hun partners.

Bij het invullen van de vragen is een aantal punten van belang. Wilt u daarom de onderstaande aanwijzingen doorlezen?

- Het invullen van de vragenlijst duurt ongeveer 30 minuten.
- De ingevulde antwoorden worden als zeer vertrouwelijk beschouwd en zullen als zodanig behandeld worden. Alleen de onderzoekers hebben toegang tot de antwoorden uit de vragenlijst, terwijl persoonlijke gegevens van deelnemers bij hen niet bekend zijn. Uw deelname aan het onderzoek is geheel vrijwillig en u kunt te allen tijde besluiten om uzelf, om welke reden dan ook, terug te trekken uit het onderzoek.
- Lees iedere vraag aandachtig door en neem de tijd voor het invullen van de antwoorden. Kies steeds het antwoord dat het meest op u van toepassing is.
- Wilt u wanneer u begint met de vragenlijst het **respondentnummer** invullen dat in de brief staat vermeld? Dit nummer wordt door de onderzoekers alleen gebruikt om gegevens van Ménière patiënten en hun partners bij de analyse aan elkaar te koppelen.
- Wilt u de vragenlijst **alleen** invullen en niet met uw partner over de vragen spreken totdat u beiden de lijst heeft ingevuld? Dit is van belang voor het welslagen van het onderzoek.
- Wilt u slechts één antwoord per vraag geven, tenzij anders wordt vermeld?
- Er zijn geen goede of slechte antwoorden mogelijk. Het gaat erom dat u de vragen zo eerlijk mogelijk beantwoordt en uw eigen mening geeft. Het is het beste niet te lang na te denken over de vragen.
- Het is voor het onderzoek van belang dat u de vragenlijst volledig invult. U wordt verzocht alleen vragen over te slaan als dat aangegeven wordt.
- Wanneer u nog vragen heeft dan kunt u contact opnemen met de onderzoekers. De gegevens van de onderzoekers staan vermeld in de brief die u hebt gekregen.

Op de laatste pagina is er een mogelijkheid om opmerkingen over de vragen te maken.

Hartelijk dank voor uw medewerking!

Vragenlijst Ménière Patiënten

Onderdeel 1

1. Wat is uw respondentnummer?

_____

De Ziekte van Ménière wordt gekenmerkt door aanvallen van draaiduizeligheid, tinnitus (oorsuizen) en gehoorverlies.

2. Hoe lang heeft u (naar schatting) last van aanvallen van draaiduizeligheid?
___ jaar

3. Hoe lang heeft u (naar schatting) last van tinnitus?
___ jaar

4. Hoe lang heeft u (naar schatting) last van gehoorverlies?
___ jaar

5. Hoe lang geleden is (naar schatting) de diagnose 'Ziekte van Ménière' gesteld?
___ jaar

6. Door wie is bij u de ziekte van Ménière vastgesteld?
U mag meerdere hokjes aankruisen.
□ KNO-arts
□ Andere medisch specialist
□ Huisarts
□ Zelfdiagnose
□ Anders, namelijk _____

7. Wat is de mate van <u>ernst</u> van uw draaiduizeligheid van de *afgelopen 3 maanden* op een schaal van 1 tot 10?

Geen probleem Kan niet erger

□	□	□	□	□	□	□	□	□	□
1	2	3	4	5	6	7	8	9	10

8. Waar hoort u tinnitus?
□ In één oor
□ In beide oren
□ Niet van toepassing

9. Wat is de mate van <u>ernst</u> van uw tinnitus van de *afgelopen 3 maanden* op een schaal van 1 tot 10?

Geen probleem Kan niet erger

□	□	□	□	□	□	□	□	□	□
1	2	3	4	5	6	7	8	9	10

10. Aan welk oor heeft u last van gehoorverlies?

□ Aan één oor
□ Aan beide oren
□ Niet van toepassing

11. Wat is de mate van <u>ernst</u> van uw gehoorverlies van de *afgelopen 3 maanden* op een schaal van 1 tot 10?

Geen probleem									Kan niet erger
□	□	□	□	□	□	□	□	□	□
1	2	3	4	5	6	7	8	9	10

12. Zijn er naast de ziekte van Ménière nog andere chronische aandoeningen bij u vastgesteld?
Een ziekte wordt chronisch genoemd als deze langer duurt dan drie maanden.

□ Ja, namelijk _____
□ Nee

13. Bent u als gevolg van de ziekte van Ménière geheel of gedeeltelijk arbeidsongeschikt verklaard voor uw werk?

□ Ja, geheel arbeidsongeschikt verklaard
□ Ja, gedeeltelijk arbeidsongeschikt verklaard
□ Ja, maar ik ben andere werkzaamheden gaan verrichten
□ Nee, ik ben niet arbeidsongeschikt verklaard
□ Nee, deze situatie is op mij niet van toepassing

Onderdeel 2

In deze vragenlijst wordt naar uw gezondheid gevraagd. Wilt u elke vraag beantwoorden door het juiste hokje aan te kruisen. Wanneer u twijfelt over het antwoord op een vraag, probeer dan het antwoord te geven dat het meest van toepassing is.

1. Wat vindt u, over het algemeen genomen, van uw gezondheid?

- ☐ Uitstekend
- ☐ Zeer goed
- ☐ Goed
- ☐ Matig
- ☐ Slecht

2. *In vergelijking met een jaar geleden*, hoe zou u *nu* uw gezondheid in het algemeen beoordelen?

- ☐ Veel beter dan een jaar geleden
- ☐ Iets beter dan een jaar geleden
- ☐ Ongeveer hetzelfde als een jaar geleden
- ☐ Iets slechter dan een jaar geleden
- ☐ Veel slechter dan een jaar geleden

3. Had u, ten gevolge van uw lichamelijke gezondheid, *de afgelopen 4 weken* één van de volgende problemen bij uw werk of andere dagelijkse bezigheden?

3a. U heeft *minder tijd* kunnen besteden aan werk of andere bezigheden.

- ☐ Ja
- ☐ Nee

3b. U heeft *minder bereikt* dan u zou willen.

- ☐ Ja
- ☐ Nee

3c. U was beperkt in het *soort* werk of het *soort* bezigheden.

- ☐ Ja
- ☐ Nee

3d. U had moeite met het werk of andere bezigheden (het kostte u bijvoorbeeld extra inspanning).

- ☐ Ja
- ☐ Nee

4. Had u, ten gevolge van een <u>emotioneel probleem</u> (bijvoorbeeld doordat u zich depressief of angstig voelde), *de afgelopen 4 weken* één van de volgende problemen bij uw werk of andere dagelijkse bezigheden?

4a. U heeft *minder tijd* kunnen besteden aan werk of andere bezigheden.

- ☐ Ja
- ☐ Nee

4b. U heeft *minder bereikt* dan u zou willen.

□ Ja

□ Nee

4c. U heeft het werk of andere bezigheden niet zo zorgvuldig gedaan als u gewend bent.

□ Ja

□ Nee

5. In hoeverre heeft uw lichamelijke gezondheid of hebben uw emotionele problemen u de *afgelopen 4 weken* belemmerd in uw normale sociale bezigheden met gezin, vrienden, buren of anderen?

□ Helemaal niet

□ Enigszins

□ Nogal

□ Veel

□ Heel erg veel

6. *Hoe vaak* hebben uw lichamelijke gezondheid of emotionele problemen gedurende de *afgelopen 4 weken* uw sociale activiteiten (zoals bezoek aan vrienden of naaste familieleden) belemmerd?

□ Voortdurend

□ Meestal

□ Soms

□ Zelden

□ Nooit

7. Deze vragen gaan over hoe u zich *de afgelopen 4 weken* heeft gevoeld.
Wilt u bij elke vraag het antwoord aankruisen dat het beste aansluit bij hoe u zich heeft gevoeld.

Hoe vaak gedurende *de afgelopen 4 weken*:	**Voort-durend**	**Meestal**	**Vaak**	**Soms**	**Zelden**	**Nooit**
a. voelde u zich levenslustig?	□	□	□	□	□	□
b. voelde u zich erg energiek?	□	□	□	□	□	□
c. voelde u zich uitgeblust?	□	□	□	□	□	□
d. voelde u zich moe?	□	□	□	□	□	□

8. In welke mate heeft u tijdens het afgelopen jaar problemen ervaren in de communicatie met uw partner in verband met achteruitgang van uw gehoor?

□ Voortdurend
□ Meestal
□ Soms
□ Zelden
□ Nooit

9. In welke mate heeft u tijdens het afgelopen jaar problemen ervaren in het ondernemen van gezamenlijke activiteiten in verband met uw ziekte van Ménière?

□ Voortdurend
□ Meestal
□ Soms
□ Zelden
□ Nooit

10. Maakt u zich in het dagelijks leven zorgen om uw partner?

□ Zelden of nooit
□ Af en toe
□ Regelmatig
□ Erg vaak

11. Hoe zou u in het algemeen de kwaliteit van leven beoordelen op een schaal van 1 tot 10?

Slechtst mogelijke kwaliteit van leven									Best mogelijke kwaliteit van leven
□	□	□	□	□	□	□	□	□	□
1	2	3	4	5	6	7	8	9	10

12. Hoe zou u de kwaliteit van leven beoordelen als u geen ziekte van Ménière zou hebben op een schaal van 1 tot 10?

Slechtst mogelijke kwaliteit van leven									Best mogelijke kwaliteit van leven
□	□	□	□	□	□	□	□	□	□
1	2	3	4	5	6	7	8	9	10

Onderdeel 3

De volgende uitspraken richten zich op de manier waarop uw partner omgaat met het feit dat u de ziekte van Ménière heeft. Het is de bedoeling dat u aangeeft in welke mate uw partner handelt of niet handelt op de beschreven wijze.

Kruis uw antwoord aan. Mijn partner handelt ..... op deze wijze.

Nooit **Zelden** **Nu en dan** **Vrij vaak** **Zeer vaak**
□ □ □ □ □

Uitspraken:	**Nooit**	**Zelden**	**Nu en dan**	**Vrij vaak**	**Zeer vaak**
1. Mijn partner probeert er open over te praten.	□	□	□	□	□
2. Mijn partner probeert me met een smoesje zover te krijgen dat ik me aan (medische) voorschriften houd.	□	□	□	□	□
3. Mijn partner vraagt hoe ik me voel.	□	□	□	□	□
4. Mijn partner probeert er samen over te praten, wanneer ik ergens mee zit.	□	□	□	□	□
5. Mijn partner probeert haar/zijn zorgen over hoe het met mij gaat voor zich te houden.	□	□	□	□	□
6. Mijn partner probeert te doen alsof er niets aan de hand is.	□	□	□	□	□
7. Mijn partner geeft maar toe, wanneer ik ergens moeilijk over doe.	□	□	□	□	□
8. Mijn partner wuift mijn zorgen gewoon weg.	□	□	□	□	□

Uitspraken:	Nooit	Zelden	Nu en dan	Vrij vaak	Zeer vaak
9. Mijn partner doet er alles voor om te zorgen dat ik zo weinig mogelijk aan mijn ziekte denk.	□	□	□	□	□
10. Mijn partner kan er niet tegen wanneer ik bezorgd ben, dan doet mijn partner maar of zij/hij het niet merkt.	□	□	□	□	□
11. Mijn partner neemt mij zoveel mogelijk werk uit handen.	□	□	□	□	□
12. Mijn partner toont begrip voor mij.	□	□	□	□	□
13. Mijn partner geeft me het gevoel dat ik er niet alleen voor sta.	□	□	□	□	□

Onderdeel 4

Wij willen graag weten hoe u zich de laatste tijd heeft gevoeld. U kunt de vragen beantwoorden door het antwoord dat het meest op u van toepassing is aan te kruisen. Het gaat bij deze vragen om hoe u zich de laatste tijd (in het bijzonder de afgelopen 4 weken) voelde, dus niet om hoe u zich in het verleden heeft gevoeld.

1. Ik voel me de laatste tijd gespannen.

- ☐ Meestal
- ☐ Vaak
- ☐ Af en toe, soms
- ☐ Helemaal niet

2. Ik geniet nog steeds van de dingen waar ik vroeger van genoot.

- ☐ Zeker zo veel
- ☐ Niet helemaal zoveel
- ☐ Weinig
- ☐ Eigenlijk helemaal niet

3. Ik krijg de laatste tijd het angstige gevoel alsof er elk moment iets vreselijks kan gebeuren.

- ☐ Heel zeker en vrij erg
- ☐ Ja, maar niet zo erg
- ☐ Een beetje, maar ik maak me er geen zorgen over
- ☐ Helemaal niet

4. Ik kan lachen en de dingen van de vrolijke kant zien.

- ☐ Net zoveel als vroeger
- ☐ Niet zo goed meer nu
- ☐ Beslist niet zoveel als vroeger
- ☐ Helemaal niet

5. Ik maak me de laatste tijd ongerust.

- ☐ Heel erg vaak
- ☐ Vaak
- ☐ Af en toe
- ☐ Zelden of nooit

6. Ik voel me de laatste tijd opgewekt.

- ☐ Helemaal niet
- ☐ Niet vaak
- ☐ Soms
- ☐ Meestal

7. Ik kan de laatste tijd rustig zitten en me ontspannen.

- ☐ Zeker
- ☐ Meestal
- ☐ Niet vaak
- ☐ Helemaal niet

8. Ik voel me de laatste tijd alsof alles moeizamer gaat.

- ☐ Bijna altijd
- ☐ Heel vaak
- ☐ Soms
- ☐ Helemaal niet

9. Ik krijg de laatste tijd een soort benauwd, gespannen gevoel in mijn maag.

- ☐ Helemaal niet
- ☐ Soms
- ☐ Vrij vaak
- ☐ Heel vaak

10. Ik heb de laatste tijd geen interesse meer in mijn uiterlijk.

- ☐ Zeker
- ☐ Niet meer zoveel als ik zou moeten
- ☐ Mogelijk wat minder
- ☐ Evenveel interesse als voorheen

11. Ik voel me de laatste tijd rusteloos.

- ☐ Heel erg
- ☐ Tamelijk veel
- ☐ Niet erg veel
- ☐ Helemaal niet

12. Ik verheug me van te voren al op dingen.

- ☐ Net zoveel als vroeger
- ☐ Een beetje minder dan vroeger
- ☐ Zeker minder dan vroeger
- ☐ Bijna nooit

13. Ik krijg de laatste tijd plotseling gevoelens van angst of paniek.

- ☐ Zeer vaak
- ☐ Tamelijk vaak
- ☐ Niet erg vaak
- ☐ Helemaal niet

14. Ik kan van een goed boek genieten, of van een radio- of televisieprogramma.

- ☐ Vaak
- ☐ Soms
- ☐ Niet vaak
- ☐ Zelden

Onderdeel 5

De volgende uitspraken hebben betrekking op de manier waarop u omgaat met uw partner **gezien het feit dat u <u>zelf</u> de ziekte van Ménière heeft**. Het is de bedoeling dat u aangeeft in hoeverre u iets wel of niet doet.

Kruis uw antwoord aan. Ik handel ..... op deze wijze.

Nooit **Zelden** **Nu en dan** **Vrij vaak** **Zeer vaak**
□ □ □ □ □

Uitspraken	**Nooit**	**Zelden**	**Nu en dan**	**Vrij vaak**	**Zeer vaak**
1. Ik probeer er met mijn partner open over te praten.	□	□	□	□	□
2. Ik vraag mijn partner hoe zij/hij zich voelt.	□	□	□	□	□
3. Wanneer mijn partner ergens mee zit, probeer ik er samen over te praten.	□	□	□	□	□
4. Ik probeer mijn zorgen over hoe het met mijn partner gaat voor me te houden.	□	□	□	□	□
5. Ik probeer te doen alsof er niets aan de hand is.	□	□	□	□	□
6. Wanneer mijn partner ergens moeilijk over doet, geef ik maar toe.	□	□	□	□	□
7. Zorgen van mijn partner wuif ik gewoon weg.	□	□	□	□	□
8. Ik doe er alles voor om te zorgen dat mijn partner zo weinig mogelijk aan mijn ziekte denkt.	□	□	□	□	□

Uitspraken	Nooit	Zelden	Nu en dan	Vrij vaak	Zeer vaak
9. Ik kan er gewoon niet tegen wanneer mijn partner bang en bezorgd is, dan doe ik maar gewoon of ik het niet merk.	□	□	□	□	□
10. Ik neem mijn partner zoveel mogelijk werk uit handen.	□	□	□	□	□
11. Ik toon begrip voor mijn partner.	□	□	□	□	□
12. Ik geef mijn partner het gevoel dat zij/hij er niet alleen voor staat.	□	□	□	□	□

Onderdeel 6

Hieronder vindt u een lijst met diverse uitspraken van mensen met een langdurige ziekte. Wij willen u vragen aan te geven in welke mate u het met deze uitspraken eens bent. U doet dit door één van de antwoordmogelijkheden achter de uitspraak aan te kruisen.

*Hieronder vindt u een **voorbeeld** van de manier waarop u de uitspraken kunt beantwoorden.*

Voorbeeld:

*Als u het **in sterke mate** eens bent met de onderstaande uitspraak, dan kruist u de derde antwoordcategorie aan.*

	Niet	Een beetje	In sterke mate	Helemaal
Ik heb met de Ziekte van Ménière leren leven.	□	□	□	□

Op deze manier werkt u de gehele lijst uitspraak voor uitspraak af. Denkt u niet te lang na en geef uw eerste indruk; die is meestal de beste.

In welke mate bent u het ermee eens?	**Niet**	**Een beetje**	**In sterke mate**	**Helemaal**
1. Ik kan de problemen, die mijn ziekte van Ménière met zich mee brengt aan.	□	□	□	□
2. Ik heb met de ziekte van Ménière leren leven.	□	□	□	□
3. Ik heb de beperkingen van mijn ziekte van Ménière leren aanvaarden.	□	□	□	□
4. Ik kan mijn ziekte van Ménière goed accepteren.	□	□	□	□
5. Ik denk dat ik de problemen van mijn ziekte van Ménière aan kan, zelfs als de aandoening erger wordt.	□	□	□	□
6. Ik kan goed met mijn ziekte van Ménière omgaan.	□	□	□	□

Onderdeel 7

De relatie met uw partner
Op deze en de volgende bladzijden zult u een aantal vragen aantreffen, die betrekking hebben op uw huwelijk of vaste relatie.

Iedere vraag wordt gevolgd door een reeks mogelijke antwoorden, die variëren van 0 - 8. De bedoeling is dat u naar de vraag en de daarbij behorende antwoorden kijkt en dan beslist welk antwoord op u het meest van toepassing is. Dit antwoord kruist u dan aan. Als uw situatie valt tussen twee van de voorgedrukte antwoorden dan kruist u het getal aan wat er tussen in staat.

1. Is uw partner voor u als persoon aantrekkelijk? (afgezien van lichamelijke aantrekkelijkheid)

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Erg aan-trekkelijk		Aan-trekkelijk		Redelijk aan-trekkelijk		Niet erg aan-trekkelijk		Onaan-trekkelijk

2. Krijgt u genoeg warmte en begrip van uw partner?

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Tevreden met warmte en begrip		Iets te weinig		Te weinig		Beslist te weinig		Groot gebrek aan warmte en begrip

3. Neemt uw partner haar/zijn deel van de verantwoordelijkheid in het huwelijk / de relatie op zich?

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Altijd neemt zij/hij haar of zijn deel op zich		Vaak		Meestal		Soms		Nooit neemt zij/hij haar of zijn deel op zich

4. Bent u tevreden over de vrije tijd die u tezamen doorbrengt?

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Erg Tevreden		Zou iets meer samen willen doen		Zou meer samen willen doen		Zou veel meer samen willen doen		Erg on-tevreden

5. Hoe vaak denkt u er aan van uw partner te scheiden?

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Vrijwel nooit		Zelden		Soms		Vaak		Op 't punt te scheiden of uit elkaar te gaan

6. Als u een woordenwisseling heeft, kunt u dan tot een overeenstemming komen?

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Meestal redelijke overeen-stemming		Meestal overeen-stemming maar met enige moeite bereikt		Flink wat geruzie voordat overeen-stemming is bereikt		Veel ruzie waar je niks mee opschiet, de overeen-stemming is voor beide weinig bevredi-gend		Er wordt nooit overeen-stemming bereikt

7. Hoe vaak is er sprake van bekvechten, gevit, spanningen, koele verstandhouding of geweld tussen u beiden?

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Redelijk goed en warme relatie		Enige span-ningen af en toe ruzie of koele verstand-houding		Nogal eens ruzie of koele verstand-houding		Tamelijk vaak ruzie of constant onenigheid		Onver-draaglijke ruzie en/of geweld

8. Heeft u het gevoel dat uw partner een goede of een slechte echtgeno(o)t(e) is?

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Erg goed		Beter dan gemiddeld		Ongeveer gemiddeld		Slechter dan gemiddeld		Erg slecht

9. Kunt u uw partner zoveel vertellen als u wilt?

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Zo eerlijk en openhartig als ik wil		Meestal openlijk, soms verberg ik meer dan ik zou willen		Ik verberg beslist meer dan ik zou willen		Ik verberg veel meer dan ik zou willen		Bijna nooit kan ik iets vertellen

10. Hoe tevreden bent u over het leven met uw partner (afgezien van seks)?

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Volkomen tevreden		Meestal tevreden		Matig tevreden		On-tevreden		Volkomen on-tevreden

11. Hoe tevreden bent u met hoe vaak u elkaar knuffelt, kust en aanraakt?

□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8
Tevreden		Zou iets beter kunnen		Matig tevreden		On-tevreden		Erg on-tevreden

12. In hoeverre is uw relatie met uw partner veranderd, als gevolg van de ziekte van Ménière?

Erg negatief veranderd	Negatief veranderd	Enigszins negatief veranderd	Geen verandering	Enigszins positief veranderd	Positief veranderd	Erg positief veranderd
□ **- 3**	□ **- 2**	□ **-1**	□ **0**	□ **1**	□ **2**	□ **3**

13. In hoeverre is uw *seksuele* relatie met uw partner veranderd, als gevolg van de ziekte van Ménière?

Erg negatief veranderd	Negatief veranderd	Enigszins negatief veranderd	Geen verandering	Enigszins positief veranderd	Positief veranderd	Erg positief veranderd
□ **- 3**	□ **- 2**	□ **-1**	□ **0**	□ **1**	□ **2**	□ **3**

14. Hoe beoordeelt u de relatie met uw partner op een schaal van 1 tot 10?

Slechtst mogelijke relatie — Best mogelijke relatie

□ **1** □ **2** □ **3** □ **4** □ **5** □ **6** □ **7** □ **8** □ **9** □ **10**

15. Hoe zou u de relatie met uw partner beoordelen als u geen ziekte van Ménière zou hebben op een schaal van 1 tot 10?

Slechtst mogelijke relatie — Best mogelijke relatie

□ **1** □ **2** □ **3** □ **4** □ **5** □ **6** □ **7** □ **8** □ **9** □ **10**

Onderdeel 8

Tot slot willen we u nog enkele vragen stellen met betrekking tot uw achtergrond.

1. Wat is uw leeftijd?
___ jaar

2. Wat is uw geslacht?
□ Man
□ Vrouw

3. Wat is uw burgerlijke staat?
□ Gehuwd
□ Samenwonend
□ Partner, niet samenwonend

4. Wat is de duur van uw huidige relatie?
___ jaar

5. Wat is de hoogste door u met succes voltooide opleiding?
□ Geen
□ Lager Algemeen Onderwijs, Basisonderwijs
□ Lager Beroeps Onderwijs: zoals huishoudschool, LTS, LEAO en LHNO
□ Middelbaar Algemeen Onderwijs: zoals MAVO, IVO en (M)ULO
□ Middelbaar Beroeps Onderwijs: zoals MTS, UTS, MBA en MEAO
□ Voortgezet Algemeen Onderwijs: zoals HAVO, VWO, Gymnasium en HBS
□ Hoger Beroeps Onderwijs: zoals HTS, HEAO en HBO
□ Wetenschappelijk Onderwijs

6. Kunt u aangeven tot welke van de onderstaande groepen u behoort? Wilt u de antwoordcategorie aankruisen die in eerste plaats op u van toepassing is?
□ Ik ben full-time/ part-time werkend
□ Ik zoek werk na verlies van mijn vorige baan
□ Ik zoek voor het eerst of na een langdurige onderbreking werk
□ Ik ben scholier/ student
□ Ik doe het huishouden
□ Ik ben gepensioneerd
□ Ik ben met vervroegd pensioen (FPU)
□ Ik ben geheel arbeidsongeschikt
□ Ik ben gedeeltelijk arbeidsongeschikt
□ Ik doe onbetaald werk met behoud van uitkering/ ik doe vrijwilligerswerk
□ Anders, namelijk _____

7. Heeft u tips voor andere mensen met de ziekte van Ménière en/of hun partners?

_____

Dit is het einde van de vragenlijst.
Hartelijk bedankt voor het invullen van de vragenlijst.
Indien u nog iets op wilt merken, dan kan dat hieronder:

Vragenlijst Partners van Ménière Patiënten

Onderdeel 1

1. **Wat is uw respondentnummer?**

   _____

2. **Hoe lang geleden is bij uw partner (naar schatting) de diagnose 'Ziekte van Ménière' gesteld?**
   ___ **jaar**

3. **Is de 'Ziekte van Ménière' ook bij u zelf vastgesteld?**
   Ja ** *zie toelichting.*
   Nee

4. **Zijn er bij u zelf nog andere chronische aandoeningen vastgesteld?**
   Een ziekte wordt chronisch genoemd als deze langer duurt dan drie maanden.
   Ja, namelijk _____
   Nee

** Vanwege de zeldzame situatie dat beide partners de 'Ziekte van Ménière' hebben, is besloten om hiervoor geen extra vragenlijst aan deze partner-enquête toe te voegen. Indien de 'Ziekte van Ménière' tevens bij u zelf is vastgesteld, bent u in dat geval bereid een korte extra vragenlijst in te vullen? Wanneer u hiertoe bereid bent, zouden wij u willen verzoeken om contact op te nemen met de NVVS (de gegevens staan vermeld in de brief), dan zullen zij u de extra vragenlijst toezenden.

Onderdeel 2

1. In welke mate heeft u tijdens het afgelopen jaar problemen ervaren in de communicatie met uw partner in verband met achteruitgang van zijn of haar gehoor?

Voortdurend
Meestal
Soms
Zelden
Nooit

2. In welke mate heeft u tijdens het afgelopen jaar problemen ervaren in het ondernemen van gezamenlijke activiteiten in verband met de ziekte van Ménière van uw partner?

Voortdurend
Meestal
Soms
Zelden
Nooit

3. Hoe vaak heeft de ziekte van Ménière van uw partner uw sociale activiteiten (zoals bezoek aan vrienden of naaste familieleden) belemmerd?

- ☐ Voortdurend
- ☐ Meestal
- ☐ Soms
- ☐ Zelden
- ☐ Nooit

4. Hoe vaak heeft u zelf activiteiten ondernomen zonder uw partner, als gevolg van het feit dat hij/zij de ziekte van Ménière heeft? (sociale activiteiten zoals bezoek aan vrienden of familie, of activiteiten m.b.t. hobby of ontspanning?)

- ☐ Voortdurend
- ☐ Meestal
- ☐ Soms
- ☐ Zelden
- ☐ Nooit

5. Bent u hier tevreden over?

- ☐ Ik onderneem zelf genoeg activiteiten
- ☐ Ik zou zelf wel iets meer activiteiten willen ondernemen
- ☐ Ik onderneem zelf nog veel te weinig activiteiten
- ☐ Ik heb er geen behoefte aan om zelf activiteiten te ondernemen

6. Hoe zou u in het algemeen de kwaliteit van *uw* leven beoordelen op een schaal van 1 tot 10?

Slechtst mogelijke kwaliteit van leven									Best mogelijke kwaliteit van leven
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
1	2	3	4	5	6	7	8	9	10

7. Hoe zou u de kwaliteit van *uw* leven beoordelen als uw partner geen ziekte van Ménière zou hebben op een schaal van 1 tot 10?

Slechtst mogelijke kwaliteit van leven									Best mogelijke kwaliteit van leven
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
1	2	3	4	5	6	7	8	9	10

Onderdeel 3

De volgende uitspraken hebben betrekking op de manier waarop u omgaat met het feit dat uw partner de ziekte van Ménière heeft. Het is de bedoeling dat u aangeeft in hoeverre u iets wel of niet doet.

Kruis uw antwoord aan. Ik handel ..... op deze wijze.

Nooit **Zelden** **Nu en dan** **Vrij vaak** **Zeer vaak**
□ □ □ □ □

Uitspraken:	**Nooit**	**Zelden**	**Nu en dan**	**Vrij vaak**	**Zeer vaak**
1. Ik probeer er met mijn partner open over te praten.	□	□	□	□	□
2. Vaak probeer ik met een smoesje mijn partner zover te krijgen dat zij/hij zich aan de (medische) voorschriften houdt.	□	□	□	□	□
3. Ik vraag mijn partner hoe zij/hij zich voelt.	□	□	□	□	□
4. Wanneer mijn partner ergens mee zit, probeer ik er samen over te praten.	□	□	□	□	□
5. Ik probeer mijn zorgen over hoe het met mijn partner gaat voor me te houden.	□	□	□	□	□
6. Ik probeer te doen alsof er niets aan de hand is.	□	□	□	□	□
7. Wanneer mijn partner ergens moeilijk over doet, geef ik maar toe.	□	□	□	□	□
8. Zorgen van mijn partner wuif ik gewoon weg.	□	□	□	□	□

Uitspraken:	Nooit	Zelden	Nu en dan	Vrij vaak	Zeer vaak
9. Ik doe er alles voor om te zorgen dat mijn partner zo weinig mogelijk aan haar/zijn ziekte denkt.	□	□	□	□	□
10. Ik kan er gewoon niet tegen wanneer mijn partner bang en bezorgd is, dan doe ik maar gewoon of ik het niet merk.	□	□	□	□	□
11. Ik neem mijn partner zoveel mogelijk werk uit handen.	□	□	□	□	□
12. Ik toon begrip voor mijn partner.	□	□	□	□	□
13. Ik geef mijn partner het gevoel dat zij/hij er niet alleen voor staat.	□	□	□	□	□

Onderdeel 5

*De volgende uitspraken richten zich op de manier waarop uw partner met **u** omgaat **gezien het feit dat zij/hij de ziekte van Ménière heeft**. Het is de bedoeling dat u aangeeft in welke mate uw partner handelt of niet handelt op de beschreven wijze.*

Kruis uw antwoord aan. Mijn partner handelt ..... op deze wijze.

Nooit **Zelden** **Nu en dan** **Vrij vaak** **Zeer vaak**
□ □ □ □ □

Uitspraken:	**Nooit**	**Zelden**	**Nu en dan**	**Vrij vaak**	**Zeer vaak**
1. Mijn partner probeert er open over te praten.	□	□	□	□	□
2. Mijn partner vraagt hoe ik me voel.	□	□	□	□	□
3. Mijn partner probeert er samen over te praten, wanneer ik ergens mee zit.	□	□	□	□	□
4. Mijn partner probeert haar/zijn zorgen over hoe het met mij gaat voor zich te houden.	□	□	□	□	□
5. Mijn partner probeert te doen alsof er niets aan de hand is.	□	□	□	□	□
6. Mijn partner geeft maar toe, wanneer ik ergens moeilijk over doe.	□	□	□	□	□
7. Mijn partner wuift mijn zorgen gewoon weg.	□	□	□	□	□
8. Mijn partner doet er alles voor om te zorgen dat ik zo weinig mogelijk aan haar/zijn ziekte denk.	□	□	□	□	□

Uitspraken:	Nooit	Zelden	Nu en dan	Vrij vaak	Zeer vaak
9. Mijn partner kan er niet tegen wanneer ik bezorgd ben, dan doet mijn partner maar of zij/hij het niet merkt.	□	□	□	□	□
10. Mijn partner neemt mij zoveel mogelijk werk uit handen.	□	□	□	□	□
11. Mijn partner toont begrip voor mij.	□	□	□	□	□
12. Mijn partner geeft me het gevoel dat ik er niet alleen voor sta.	□	□	□	□	□

Onderdeel 6

Hieronder vindt u een lijst met diverse uitspraken van mensen die een partner hebben met een langdurige ziekte, met wie zij een (vaste) relatie hebben. Wij willen u vragen aan te geven in welke mate u het met deze uitspraken eens bent. U doet dit door één van de antwoordmogelijkheden achter de uitspraak aan te kruisen.

*Hieronder vindt u een **voorbeeld** van de manier waarop u de uitspraken kunt beantwoorden.*

Voorbeeld:
*Als u het **in sterke mate** eens bent met de onderstaande uitspraak, dan kruist u de derde antwoordcategorie aan.*

	Niet	Een beetje	In sterke mate	Helemaal
Ik heb met de ziekte van Ménière van mijn partner leren leven.	□	□	□	□

Op deze manier werkt u de gehele lijst uitspraak voor uitspraak af. Denkt u niet te lang na en geef uw eerste indruk; die is meestal de beste.

In welke mate bent u het ermee eens?	Niet	Een beetje	In sterke mate	Helemaal
7. Ik kan de problemen, die de ziekte van Ménière van mijn partner met zich mee brengt aan.	□	□	□	□
8. Ik heb met de ziekte van Ménière van mijn partner leren leven.	□	□	□	□
9. Ik heb de beperkingen van de ziekte van Ménière van mijn partner leren aanvaarden.	□	□	□	□
10. Ik kan de ziekte van Ménière van mijn partner goed accepteren.	□	□	□	□
11. Ik denk dat ik de problemen van de ziekte van Ménière van mijn partner aan kan, zelfs als de aandoening erger wordt.	□	□	□	□
12. Ik kan goed met de ziekte van Ménière van mijn partner omgaan.	□	□	□	□

Onderdeel 8

Deze vragen hebben specifiek betrekking op het leven met uw partner en de situatie rondom de ziekte van Ménière.

1. Maakt u zich in het dagelijks leven zorgen om uw partner?

- □ Zelden of nooit
- □ Af en toe
- □ Regelmatig
- □ Erg vaak

2. Heeft u, *als gevolg van het feit dat uw partner de ziekte van Ménière heeft*, één van de volgende problemen bij uw werk of andere dagelijkse bezigheden?

2a. U heeft *minder tijd* kunnen besteden aan werk of andere bezigheden

- □ Ja
- □ Nee

2b. U heeft *minder bereikt* dan u zou willen

- □ Ja
- □ Nee

2c. U was beperkt in het *soort* werk of het *soort* bezigheden

- □ Ja
- □ Nee

2d. U had moeite met het werk of andere bezigheden (het kostte u bijvoorbeeld extra inspanning)

- □ Ja
- □ Nee

2e. U heeft het werk of andere bezigheden niet zo zorgvuldig gedaan als u gewend bent

- □ Ja
- □ Nee

3. Hoe ervaart u reacties vanuit uw omgeving voor de situatie van uw partner?
Ik ervaar reacties als….

Erg onbegripvol	Onbegripvol	Enigszins onbegripvol	Neutraal	Enigszins begripvol	Begripvol	Erg begripvol
□	□	□	□	□	□	□
- 3	**- 2**	**-1**	**0**	**1**	**2**	**3**

4. Hoe ervaart u reacties vanuit uw omgeving voor de situatie van uzelf?
Ik ervaar reacties als….

Erg onbegripvol	Onbegripvol	Enigszins onbegripvol	Neutraal	Enigszins begripvol	Begripvol	Erg begripvol
□	□	□	□	□	□	□
- 3	**- 2**	**-1**	**0**	**1**	**2**	**3**

5. Hoe ervaart u *hulp of steun* vanuit uw omgeving voor de situatie van uw partner?

Altijd negatieve hulp en steun	Meestal negatieve hulp en steun	Soms negatieve hulp en steun	Neutrale hulp en steun	Soms positieve hulp en steun	Meestal positieve hulp en steun	Altijd positieve hulp en steun
□	□	□	□	□	□	□
- 3	**- 2**	**-1**	**0**	**1**	**2**	**3**

6. Hoe ervaart u *hulp of steun* vanuit uw omgeving voor de situatie van uzelf?

Altijd negatieve hulp en steun	Meestal negatieve hulp en steun	Soms negatieve hulp en steun	Neutrale hulp en steun	Soms positieve hulp en steun	Meestal positieve hulp en steun	Altijd positieve hulp en steun
□	□	□	□	□	□	□
- 3	**- 2**	**-1**	**0**	**1**	**2**	**3**

7. Wat is voor *uzelf*, als partner van een Ménière patiënt, het belangrijkste gevolg geweest van de ziekte van uw partner?

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

8. Zijn er eventueel factoren die uw leven hebben verrijkt, als gevolg van het feit dat uw partner de ziekte van Ménière heeft gekregen?

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

9. Heeft u voldoende kennis over de ziekte van Ménière?

- Ik heb genoeg kennis
- Ik zou wel iets meer willen weten
- Ik weet nog veel te weinig

10. Heeft u behoefte aan informatie over de ziekte van Ménière?

- Ik heb genoeg informatie
- Ik zou wel iets meer informatie willen hebben
- Ik heb nog veel te weinig informatie

11. Heeft u contact met andere partners van Ménière patiënten?

- Zelden of nooit
- Af en toe
- Regelmatig
- Erg vaak

12. Heeft u behoefte aan contact met andere partners van Ménière patiënten?

- Ik mis contact met andere partners en dit zou ik graag meer willen
- Ik mis contact met andere partners niet echt, maar iets vaker zou prettig zijn
- Precies goed zo, ik zou het contact niet vaker of minder vaak willen
- Ik heb te vaak contact met andere partners, het zou prettig zijn als het minder vaak zou zijn
- Ik heb geen behoefte aan contact met andere partners

13. Zijn er zaken waarin de NVVS en/of de commissie Ménière meer voor u zouden kunnen betekenen?

_____
_____
_____

14. Heeft u tips voor andere mensen met de ziekte van Ménière en/of hun partners?

_____
_____
_____

Dit is het einde van de vragenlijst.
Hartelijk bedankt voor het invullen van de vragenlijst.
Indien u nog iets op wilt merken, dan kan dat hieronder:

_____
_____
_____